

# Agenda – Health, Social Care and Sport Committee – Fifth Senedd

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Meeting Venue:	For further information contact:
Video Conference via Zoom	Claire Morris
Meeting date: 13 March 2019	Committee Clerk
Meeting time: 09.30	0300 200 6565
	<a href="mailto:Contact@senedd.wales">Contact@senedd.wales</a>

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- 1 Introductions, apologies, substitutions and declarations of interest**  
(09.30)
- 2 Paper(s) to note**  
(9.30)
  - 2.1 Letter from the Minister for Health and Social Services regarding use of antipsychotic medication in care homes in Wales**  
(Pages 1 – 30)
  - 2.2 Letter from the Minister for Health and Social Services regarding the All Wales Performers List**  
(Pages 31 – 36)
  - 2.3 Letter from the Minister for Health and Social Services regarding inequalities in access to hospices and palliative care.**  
(Pages 37 – 42)
  - 2.4 Letter from the Minister for Health and Social Services regarding the Healthcare (International Arrangements) Bill**  
(Pages 43 – 44)
  - 2.5 Letter from the Minister for Health and Social Services regarding the implementation of the Nurse Staffing Levels (Wales) Act 2016**  
(Pages 45 – 50)
  - 2.6 Letter from Carers Trust Wales Youth Council with additional information**  
(Pages 51 – 52)



- 2.7 Letter from Carers Trust Wales and Carers Wales regarding carers needs assessments**  
(Pages 53 – 54)
- 3 Motion under Standing Order 17.42 (vi) to resolve to exclude the public from the remainder of this meeting**  
(9.35)
- 4 Autism (Wales) Bill: Consideration of Welsh Government response**  
(9.35–10.05) (Pages 55 – 74)  
Paper 8 – Welsh Government response  
Paper 9 – Letter from National Autistic Society Cymru  
Research Brief
- 5 Endoscopy services in Wales: Consideration of draft report**  
(10.05–10.35) (Pages 75 – 106)

**Vaughan Gething AC/AM**  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

## Agenda Item 2.1



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref MA-P/VG/4386/18

Dai Lloyd AM (Chair)  
Health, Social Care and Sport Committee  
National Assembly for Wales  
Cardiff CF99 1NA

[Dai.Lloyd@assembly.wales](mailto:Dai.Lloyd@assembly.wales)

19 February 2019

Dear Dai,

Following the publication of the Health, Social Care and Sport Committee's report "Use of antipsychotic medication in care homes", I committed to establishing an expert panel to review the report and its recommendations

A short life working group was established to consider the recommendations, specifically in regards to the collection, monitoring and the reporting of data. The group was chaired by Welsh Government's Chief Pharmaceutical Officer, Andrew Evans, and met three times from August to November 2018. The resulting report includes a number of recommendations which I believe represents a proportionate approach in light of the data currently available. It also makes recommendations where improvements can, and should, be made in terms of data collection.

I attach a copy of the report for your convenience.

Yours sincerely,

**Vaughan Gething AC/AM**  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

# **Measuring the prevalence of antipsychotic use in care homes in Wales**

Report of the Short Life Working Group

January 2019

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## Summary

Antipsychotics are a group of medications usually used in the treatment of mental health conditions such as schizophrenia. There have been increasing concerns over recent years about the use of antipsychotics to treat the behavioural and psychological symptoms of dementia (BPSD).

The National Assembly for Wales' Health, Social Care and Sport Committee report the *use of antipsychotic medication in care homes in Wales* published in 2018 identifies the need to understand the extent to which antipsychotic medicines are used in the management of BPSD, particularly in care homes where previous inquiries have suggested their use may be excessive.

This report makes recommendations in relation to the use of routinely collected data to help understand the use of antipsychotic medicines amongst older people who are resident both in their own and in care homes, and more importantly to understand variation in use that, without prejudging its appropriateness, would warrant further investigation.

In reaching the recommendations in this report, members of a short life working group established by the Welsh Government considered the constraints of currently available data. Data regarding the dispensing of antipsychotic medication are comprehensive in so much as the number of prescriptions; volume and type of medications are all readily identifiable and attributable to GP practice and dispensing pharmacy. However other relevant information, including patients' ages and addresses, whilst available cannot be utilised (this is explored in section 3.3 of the report); and other information, in particular diagnoses, is not available. The short life working group were also aware of the limitations of considering all prescribing to be equivalent. In practice many patients will benefit from the considered efforts of healthcare professionals to limit antipsychotic prescribing to the lowest effective dose, for the shortest possible duration; such prescriptions cannot readily be distinguished from less prudent use at higher doses and for extended durations.

Overall members of the short life working group agreed good progress had been made by the NHS Wales Informatics Service to identify the number of people aged 65 or over prescribed antipsychotic medications in Wales. There was concern that presenting data at the level of individual care homes could be of limited value given care homes were a heterogeneous group both in size and the needs of residents; meaning data could not be standardised (this is explored in section 3.7 of the report).

Finally, members of the short life working group considered data from audits. This data indicated the risks of prescribing antipsychotic medications for the management of BPSD were not limited to residents in care homes. Demographic changes and the aspirations set out in the Welsh Government's plan for health and social care *A Healthier Wales*, would in future mean more people with dementia would be cared for in their own homes. Members of the short life working group concluded reduction in total antipsychotic medication use would benefit people regardless of where they live.

## 1 Background

### 1.1 Dementia

Dementia is caused by diseases of the brain and has symptoms which include the gradual loss of memory, reasoning and communication skills. There are different types of dementia, with the most common being Alzheimer's disease and vascular dementia.

Dementia is not a natural stage in the ageing process but a progressive illness that tends to affect the individual in a gradual manner, moving from initial memory problems to the loss of the essential elements of mental functioning. In the later stages of dementia, people can be very vulnerable because of its effects.

There are over 40,000 people living with dementia in Wales.<sup>1</sup> This is not just a problem affecting Wales; the most up-to-date statistics show that the numbers of people with dementia are rising across the UK and the world.

Anyone in society can be affected with dementia, irrespective of gender, ethnicity or class. It can affect adults of working age, people with learning disabilities and older people, with dementia becoming more common as people age. One in 14 people over 65, one in 6 people over 80, and one in three people over 95 has some form of dementia.<sup>2</sup>

### 1.2 Care homes and dementia

Many people with dementia move into care homes as their dementia progresses. Good quality care that preserves dignity, treats people with respect and promotes independence can improve the lives of people with dementia who live in care homes.

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<sup>1</sup> Alzheimer's Society. The hidden cost of dementia in Wales. 2015 Available at: [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/the\\_hidden\\_cost\\_of\\_dementia\\_in\\_wales.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/the_hidden_cost_of_dementia_in_wales.pdf) [accessed 14 November 2018]

<sup>2</sup> The Alzheimer's Society fact sheet 400. Available at: [https://www.alzheimers.org.uk/download/downloads/id/3416/what\\_is\\_dementia.pdf](https://www.alzheimers.org.uk/download/downloads/id/3416/what_is_dementia.pdf) [accessed 14 November 2018]

Many people with dementia who live in care homes have high levels of healthcare needs as a result of the cognitive, physical, psychological and behavioural symptoms of dementia. On top of this, many people with dementia who live in care homes have another physical or mental health condition such as heart disease, stroke or depression.

It is estimated the average prevalence of people living with dementia in care homes is 63% of men and 71% of women and the overall prevalence of dementia in care homes rose from 56% to 70% of residents between 2002 and 2013.<sup>3</sup>

### **1.3 Use of antipsychotic medicines in dementia**

Behavioural and psychological symptoms are common in dementia and most patients at some point in their illness will manifest these behaviours. They are the result of a complex interplay between the illness, the environment, physical health, mental wellbeing, medication and interactions with others. Although these symptoms can often remit spontaneously, they can also be persistent and severe, causing considerable distress to patients and carers and significantly impairing quality of life.

In general, antipsychotics are not licensed in the UK for the treatment of BPSD. However, antipsychotics are often prescribed off-label for this purpose.<sup>4</sup> It has been suggested that around two thirds of prescriptions of antipsychotics for people with dementia are inappropriate.<sup>5</sup>

### **1.4 Prevalence of antipsychotic prescribing in Wales**

Antipsychotics are a range of medicines that are used in the treatment of a number of mental health disorders. Most commonly they are used in the management of

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<sup>3</sup> Matthews, F et al. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II – on behalf of the Medical Research Council Cognitive Function and Ageing Collaboration. 2013.

<sup>4</sup> Szczepura A, Wild D, Khan AJ, et al Antipsychotic prescribing in care homes before and after launch of a national dementia strategy: an observational study in English institutions over a 4-year period *BMJ Open* 2016;6:e009882

<sup>5</sup> National Assembly for Wales Health, Social Care and Sport Committee – Use of anti-psychotics medication in care homes. Available at: <http://www.assembly.wales/laid%20documents/cr-ld11556/cr-ld11556-e.pdf> [Accessed 14 November 2018]

schizophrenia but they are also commonly used to treat bipolar disorder. In some cases they can also be used to help in the treatment of severe anxiety or depression.<sup>6</sup>

In 2017, 780,000 prescriptions for antipsychotic medicines were dispensed in primary care in Wales, the indications for these prescriptions are not known.<sup>7</sup> In the three month period 1 July to 30 September 2018, 9,713 individuals aged 65 or over were prescribed an antipsychotic medicine in primary care.<sup>8</sup>

### **1.5 Risks of antipsychotic use in dementia**

Antipsychotics can cause serious side effects, especially when used for long periods. Possible side effects of antipsychotics include sedation, shaking and unsteadiness, and increased risk of falls. Importantly, antipsychotics are associated with an increased risk of cerebrovascular adverse events, eg, strokes and greater mortality when used in people with dementia. Studies estimate that there are at least 1,800 extra deaths each year among people with dementia as a result of their taking antipsychotics. The likelihood of premature death increases if people take these drugs for prolonged periods (i.e. months or years rather than weeks).<sup>9</sup>

### **1.6 National Assembly for Wales Health and Social Care Committee Inquiry and Report**

In March 2017, the National Assembly for Wales' Health and Social Care Committee launched an inquiry into the use of antipsychotic medication in care homes in Wales. The inquiry concluded in May 2018 and a report containing 11 recommendations was published.

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<sup>6</sup> Royal College of Psychiatrists. Antipsychotics. Available at <https://www.rcpsych.ac.uk/mental-health/treatments-and-wellbeing/antipsychotics> [Accessed 11 January 2019]

<sup>7</sup> Welsh Government. Prescriptions dispensed in the community. Available at <https://gov.wales/statistics-and-research/prescriptions-dispensed-community/?lang=en> [Accessed 9 January 2019]

<sup>8</sup> Personal communication from the All Wales Therapeutics and Toxicology Centre.

<sup>9</sup> Banerjee S. The use of antipsychotic medication for people with dementia: Time for action. 2009. Available at: [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/PublicationsandStatistics/Publications/PublicationsPolicyAndGuidance/DH\\_108303](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/PublicationsandStatistics/Publications/PublicationsPolicyAndGuidance/DH_108303) [Accessed 14 November 2018]

Recommendations covered a wide range of areas including the inspection of care homes, access to non-pharmacological interventions for BPSD, compliance with guidance issued by the National Institute for Health and Care Excellence (NICE) and the availability of data regarding prescribing of antipsychotic medicines to care home residents. In the case of the latter the report specifically recommended:

“The Welsh Government should ensure that, within 12 months, all health boards are collecting and publishing standardised data on the use of antipsychotic medication in care homes and report back to this Committee on progress at the end of that 12 month period”

The report and its recommendations were discussed in Plenary on 11 July 2018.

### **1.7 Short life working group**

In response to the Health, Social Care and Sport Committee’s report the Cabinet Secretary for Health and Social Services committed to convene a group of relevant experts to examine the usefulness of various data sources and provide advice on how they might best be used to support the Welsh Government’s aspiration to reduce inappropriate prescribing of antipsychotic medications.

In 2018, a short life working group were established to consider the recommendations of the Health, Social Care and Sport Committee with a particular focus on:

1. Reviewing current data collection and reporting of antipsychotic prescribing in care homes;
2. Exploring ways in which repeat prescription systems could trigger the need for medication review; and
3. Providing recommendations as to where this process could be improved

The short life working group brought together representatives from key agencies involved in the collection, processing or interpretation of prescribing and care home data along with experts in social care and prescribing policy including (figure one).

Antipsychotic prescribing data short life working group membership

NHS Wales Shared Services Partnership  
NHS Wales Informatics Services  
All Wales Therapeutics and Toxicology Centre  
Care Inspectorate Wales  
Senior Medical Officers – primary care and mental health, Welsh Government  
Pharmacists – primary care and mental health, Local Health Boards  
Statisticians - Knowledge and Analytical Skills, Welsh Government  
Social Services and Integration Directorate, Welsh Government

**Figure one:** Organisations represented on short life working group

A full list of representatives and contributors is provided at Annex two.

The short life working group met three times between August and November 2018.

## 2 Measures of antipsychotic use in care homes

### Literature review

A review of relevant UK and international peer reviewed studies regarding the use of antipsychotic medicines in care homes was commissioned by the Welsh Government to support the short life working group by identifying measures of antipsychotic use and potential data collection methods.

The review identified 15 relevant studies published since 2010, which measured the extent to which antipsychotics are used in care homes, assisted living facilities or the community (annex one). It should be noted that in general these studies were designed to measure use of antipsychotics at a population level (through aggregation of data from multiple sites), measure changes in individual care homes' prescribing practice or determine the factors which are positively or negatively associated with antipsychotic use. The short life working group found no studies which reported routine comparison of care home prescribing rates for the purposes of performance management or identifying poor practice.

Measures of antipsychotic prescribing in these studies included:

- Percentage of residents prescribed antipsychotic (or other relevant) medication for routine use;
- Percentage of residents prescribed antipsychotic medication;
- Percentage of residents with dementia prescribed antipsychotic medication;
- Number of prescriptions for antipsychotic (or other relevant) medication in defined daily dosages; and
- Percentage of residents taking antipsychotic medicines for off label indications.

The literature review also identified several studies which identified factors that are positively or negatively associated with antipsychotic use such as age and gender.

### 3 Data routinely collected in Wales

#### 3.1 Summary

The short life working group prioritised identifying sources of routine data relating to:

- The number of care homes in Wales by local health board and local authority;
- The classification of care homes in particular in relation to the health needs of residents;
- The size of care homes (i.e. the number of beds);
- The demographics of care home residents;
- Data derived and routinely available from the prescription pricing process (e.g. number of prescriptions for antipsychotic medication);
- Data derived but **not** routinely available from the prescription pricing process (e.g. demographic characteristics of patients);
- Data extracted from GP practice electronic records (e.g. the National Prescribing Indicator related to antipsychotic prescribing in over 65s); and
- Data reported by community pharmacies providing the Care Home National Enhanced Service.

The short life working group also discussed data derived from audits of prescribing carried out in individual care homes and GP practices. The short life working group agreed audit provides the most detailed and comprehensive source of data regarding prescribing of antipsychotics in care homes but noted their completion is time consuming and resource intensive. The comprehensive and often qualitative nature of audit meant it might not always be suitable for measuring continuous quality improvement. The short life working group agreed that audit should be 'intelligence led' (i.e. based on signals that the practice of using antipsychotic medicines in a particular home or practice was sub-optimal), and were aware of the work undertaken to produce the Clinical Effectiveness Prescribing Programme (CEPP) *National Audit: Antipsychotics in Dementia* developed recently by the All Wales Prescribing Advisory Group (AWPAG). The short life working group agreed a consistent approach to the audit of antipsychotic use was valuable.

### **3.2 Care Homes and care home residents**

Data provided by the Care Inspectorate Wales identified there to be 1,078 care homes in Wales providing a maximum capacity of just over 25,000 care beds. The breakdown of homes and beds is shown in table one.

Detail regarding the type of service provided (e.g. whether the home included provision for mental health) by a care home was less clear, largely because such distinctions are no longer routinely made between homes. The Regulation and Inspection of Social Care (Wales) Act 2016 came into effect in April 2018 for care homes (this includes children's homes), domiciliary support services, secure accommodation services and residential family centres. The 2016 Act replaces the Care Standards Act 2000 (CSA 2000) and requires providers registered under CSA 2000 to re-register. As a result, providers will have limited conditions of registration which specify the type of service provided, the location where the service is provided and the numbers of people accommodated (accommodation based services). However, Care Inspectorate Wales (CIW) will publish an online register displaying the type of service i.e. nursing or children's home, the named registered person, and will include the age range for which the service is registered.

Data on the number of care homes and residents are also maintained by the NHS Wales Shared Services Partnership. These data were found to differ from the CIW registry; 774 care homes were identified with a total of 17,782 residents. The reasons for this difference are as follows: data maintained by the NHS Wales Shared Services Partnership are extracted from the National Health Application and Infrastructure Services (NHAIS) database of patients registered with a GP in Wales. These data therefore represent actual care home residents and not bed numbers or capacity. The data are maintained for payment purposes but rely on a GP practice identifying care home residents in the NHAIS database. Data related only to those aged 65 or over.

**Table one:** Care home premises and maximum capacity by health board and local authority (September 2018)

Health Board	Local Authority	Premises	Maximum Capacity
Abertawe Bro Morgannwg University	Bridgend	36	1033
	Neath Port Talbot	54	1166
	Swansea	86	2182
	Total	176	4381
Aneurin Bevan University	Blaenau Gwent	22	516
	Caerphilly	56	1111
	Monmouthshire	33	747
	Newport	38	914
	Torfaen	23	690
Total	172	3978	
Betsi Cadwaladr University	Conwy	74	1587
	Denbighshire	76	1492
	Flintshire	36	931
	Gwynedd	49	1156
	Isle of Anglesey	29	639
	Wrexham	39	1378
	Total	303	7183
Cardiff and Vale University	Cardiff	86	2347
	Vale of Glamorgan	42	985
	Total	128	3332
Hywel Dda University	Carmarthenshire	87	2015
	Ceredigion	24	556
	Pembrokeshire	65	1270
	Total	176	3841
Cwm Taf University	Merthyr Tydfil	18	363
	Rhondda Cynon Taf	62	1625
	Total	80	1988
Powys Teaching	Powys	40	1169
Unspecified	Total	3	53
Wales	Total	1078	25925

In common with prescribing data, GP registration data can be aggregated at GP practice, primary care cluster, local authority and local health board levels. This means it should be possible to take account of the number of care home residents in any standardisation of data for the purposes of comparison between different GP practices, primary care clusters, local authorities or local health boards (figure two).

### Standardising Prescribing Data

In order to make meaningful comparisons between prescribing between GP practices it is necessary to take account of differences in the size and demographics of the population each practice serves. The age structure of the population of each practice will differ as will the prevalence of specified diseases. The morbidity of disease, and as a result the way in which it is treated, will itself be influenced by population age structure.

In order to take account of variables such as age and disease prevalence, prescribing data is usually standardised or weighted using standardisation methods such as prescribing units. Standardisation methods are robustly developed and validated.

**Figure two:** Standardisation of prescribing data

The short life working group considered whether there would be merit in exploring whether prescribing data could be standardised taking into account the number of residents of care homes registered with GP practices. It was agreed this was not within the scope of the work the short life working group had been asked to complete. The short life working group were also aware that data on the number of residents of care homes registered with each GP practice and the proportion of the total list size they represented was in some cases small (mean number of care home residents aged 65 or over per GP practice = 46.8, Range 1 to 363, n = 396). This could mean adjusting for care home residents would have little impact on prescribing rates. Standardisation would have the effect of reducing apparent variation between care homes.

### **3.3 Data derived from the prescription pricing process**

All NHS prescriptions for medicines dispensed by community pharmacies and dispensing doctors in Wales are submitted to the NHS Wales Shared Services Partnership for 'pricing' (i.e. calculating the reimbursement and remuneration payable to the dispenser). In order to accurately calculate the reimbursement (i.e. the repayment of acquisition costs incurred by the dispenser in purchasing a medicine for supply against a prescription) payable, it is necessary to extract from each prescription the data regarding the nature (name, form and strength) of the medicine and the quantity supplied.

Data extracted from prescriptions are aggregated at the GP practice, primary care cluster, local authority and local health board levels and made available for comparative analysis by practices and health boards. The NHS Wales Shared Services Partnership Primary Care Service makes this data routinely available for analysis (figure three).

#### Prescribing data and publications

**CASPA** (Comparative Analysis System for Prescribing Audit) - a Windows application for analysis and graphical presentation of prescribing data and trends.

**Prescribing Audit Reports** (PAR) – budget statements for individual practices

**On-line catalogue** - a hierarchical view of prescribing based on British National Formulary (BNF) category with access to images of the individual prescriptions from which the data are derived.

**Figure three:** Data and publications regarding prescribing routinely available from the NHS Wales Shared Services Partnership

Data derived from the prescription pricing process allows comparison of cost and volume of prescribing both between GP practices over time (table two). Data can be standardised to take account of population differences between practices. Data are extracted from a 2D barcode generated by the GP practice prescribing system.<sup>10</sup> Data are highly accurate but limited; for example, no information is contained in the 2D barcode regarding the diagnosis underpinning the prescription. The 2D barcode does not contain any information regarding whether or not a patient is resident in a care home.

Whilst the information routinely collated from 2D barcoded prescriptions is limited to information on prescriber, cost and volume, additional potentially useful information is contained within the 2D barcode. This includes: the individual's NHS number, age, gender and postcode. However, this information cannot currently be routinely extracted from prescriptions because the NHS Wales Shared Services Partnership does not have the consent of individuals to process that data and their functions only

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<sup>10</sup> A small proportion of prescriptions are written outside GP practice prescribing systems and will not include a 2D barcode, for example prescriptions written by GPs during home visits, prescriptions written by dentists or by doctors in hospital outpatient departments

allow them to collect this data for the purpose of calculating the reimbursement and remuneration payable to the dispenser.

**Table two:** Example prescribing data: All prescriptions (items) for antipsychotic medications prescribed in Aneurin Bevan University Health Board clusters and selected practices April to June 2018.

	April	May	June
AB Unidentified Cluster	137	145	145
Blaenau Gwent East	1145	1313	1282
GP Practice 1	241	263	279
GP Practice 2	126	148	164
GP Practice 3	178	209	223
GP Practice 4	449	522	449
GP Practice 5	151	171	167
Blaenau Gwent West	1212	1330	1287
Caerphilly East	2173	2475	2212
Caerphilly North	3041	3237	2993
Caerphilly South	2871	2993	2708
Monmouthshire North	1266	1333	1348
Monmouthshire South	1097	1125	1054
Newport East	1924	1977	1913
Newport North	2236	2331	2306
Newport West	2551	2612	2528
Torfaen North	2370	2678	2319
Torfaen South	1915	2229	2086
Unknown	1811	1846	2014
Health Board Total	25749	27624	26195

The short life working group considered this to be a significant constraint on understanding the quality and appropriateness of prescribing of not only antipsychotic but also any other medication. The group agreed utilising these additional data would allow prescriptions to be:

1. Linked at the individual patient level – this would mean the length of time over which a patient had been prescribed an antipsychotic could be calculated and the number of patients prescribed antipsychotic medication for a period of three months or longer routinely presented; and
2. Aggregated by demographic characteristics such as age, gender and geographic area (e.g. Lower Super Output Area).

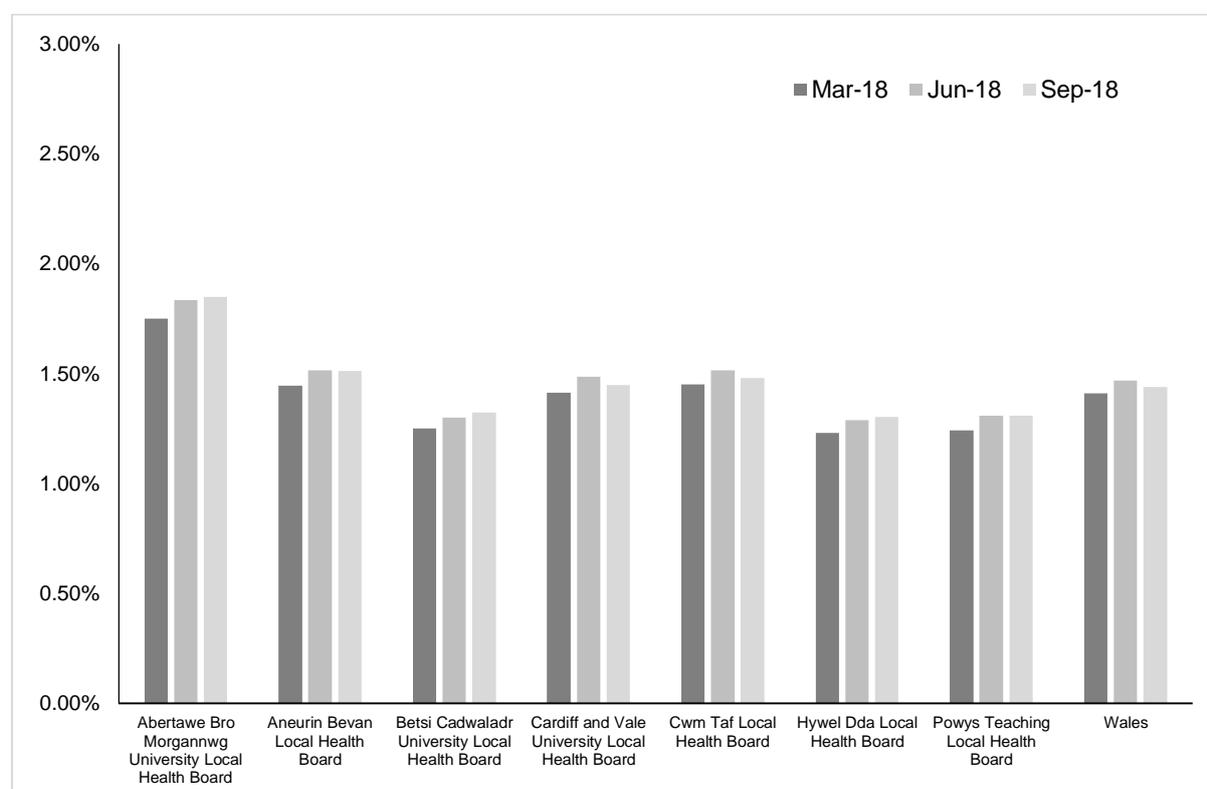
The utilisation of this data would greatly improve the understanding of prescribing behaviour. Therefore the short life working group have made a recommendation that arrangements should be reviewed and a solution sought to enable the collection, review and use of all data contained in NHS prescriptions. This work should be explored by considering the data sharing arrangements between the NHS Wales Shared Services Partnership and Public Health Wales as the latter's statutory

functions allows it to undertake the systematic collection, analysis and dissemination of information about the health of the people of Wales.

### 3.4 Data extracted from GP practice electronic records

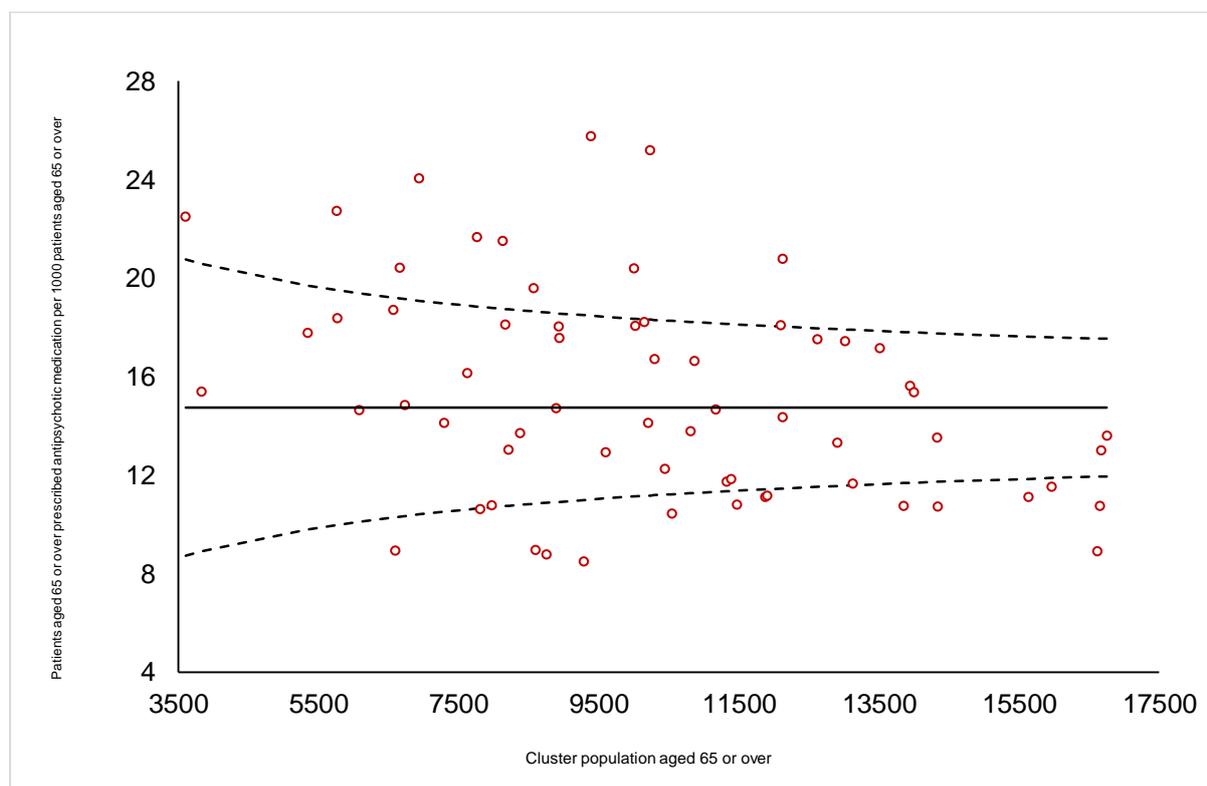
All GP practices maintain electronic patient records containing personal information, diagnoses, test results and prescription information for each individual registered with the practice. Audit+ is a third-party GP data quality, audit and reporting software tool delivered and supported by the NHS Wales Informatics Service (NWIS). It allows data contained in GP practice systems to be linked, extracted and aggregated.

Since April 2017 data derived from Audit+ have been utilised to develop national prescribing indicators. In April 2018, a national prescribing indicator was developed using linked data derived from the Audit+ system, measuring the number and percentage of patients aged 65 or over prescribed an antipsychotic medication. Data for the period March to September 2018 by health board is shown in figure four.



**Figure Four:** Percentage of GP registered population aged 65 or over and prescribed antipsychotic medication March to September 2018 by local health board

The national prescribing indicator provides a means of comparing variation in prescribing practice between primary care clusters, this includes being able to identify outlying clusters in which prescribing rates may be higher than average (figure five).



**Figure Five:** Funnel plot of antipsychotic medication prescribing rate 1000 patients aged 65 or over June to September 2018 by primary care cluster

The short life working group were aware the Health and Social Care Committee had received information about, and welcomed the introduction of, the antipsychotic patient safety indicator but also that the data did not differentiate between patients resident in care homes and in the community.

The short life working group, having considered the audit findings provided by Cardiff and Vale University Health Board, were mindful that the use of antipsychotics to manage BPSD was by no means restricted to care homes and the transformation set out in the Welsh Government’s plan for health and social care, *A Healthier Wales*, could see an increase in the number of people with dementia supported in their own homes in future.

The short life working group agreed the national prescribing indicator should be retained in its current form but that the feasibility of in addition, presenting the number of registered patients aged 65 or over, prescribed an antipsychotic and resident in a care home, should be explored. The short life working group considered the code used to identify a patient as a care home resident in the NHAIS database could provide a means of achieving this provided it could be identified using the Audit+ tool.

### **3.5 Data reported by community pharmacies providing the Care Home National Enhanced Service**

In April 2018, health boards and Community Pharmacy Wales (CPW) agreed a specification for a national community pharmacy enhanced service for care home support.

The service aims to utilise the skills and expertise of pharmacists and their teams to contribute to the optimisation of medicines use in care homes and support the reduction of waste. The service is comprised of three tiers:

- the first focussed on improved systems and processes for ordering, storing, administering and disposing of medicines;
- the second on highlighting prescribing that might be considered to be high risk (through the collection and reporting of Patient Outcome Medicines Safety Indicators or POMSI); and
- the third on medication review.

The intention is for health boards to commence commissioning the tier one and two services in 2018-19.

The tier two (POMSI) element of the service requires a pharmacy to undertake biannual reviews of residents in each care home (with an interval of not less than 4 months between each review) and report against agreed POMSI (figure six).

Community Pharmacy Care Home National Enhanced Service – Patient Outcome Medicines Safety Indicators (POMSIs)

Number of residents prescribed:

1. A proton pump inhibitor at high or treatment dose for more than 8 weeks;
2. A hypnotic or anxiolytic for more than 4 weeks;
3. Antipsychotic medication;
4. Antipsychotic medication and who have a known diagnosis of dementia;
5. Non-Steroidal Anti-inflammatory Drug (NSAID) without gastroprotection;
6. NSAID for more than 3 months;
7. Bisphosphonate tablet and who is unable to stand or sit upright for at least 30 minutes after taking;
8. A medicine or combination of medicines with a combined anticholinergic effect on cognition score of 3 or more and who is aged 75 or over;
9. Antihypertensive medication and who have not had a blood pressure check in previous 6 months; and
10. Warfarin, methotrexate or lithium and who do not have an up to date monitoring booklet.

**Figure six:** Community Pharmacy Care Home National Enhanced Service – Patient Outcome Medicines Safety Indicators (POMSIs)

A sample of data collected under the care home enhanced service is shown in table three.

**Table three:** Example antipsychotic medication POMSI for selected care homes

	Beds	Currently prescribed antipsychotic	Currently prescribed antipsychotic with known diagnosis of dementia <sup>11</sup>	% of residents prescribed antipsychotic
Care Home 1	33	0	0	0.00%
Care Home 2	20	2	0	10.00%
Care Home 3	31	2	0	6.45%
Care Home 4	40	6	2	15.00%
Care Home 5	52	1	0	1.92%

The community pharmacy enhanced service data are the only routinely collected data aggregated at the level of individual care home. The short life working group noted that at the time of preparing its report coverage of the enhanced service was low and data were available for very few care homes. The short life working group considered the POMSI relating to antipsychotic use and noted its similarity to measures reported in peer reviewed literature. Some concerns were expressed

<sup>11</sup> Community pharmacists are unlikely to have access to information to confirm a diagnosis of dementia in which case they are unable to identify residents meeting these criteria.

about the use of this data primarily related to the likely low numbers of residents in most care homes (<100) and the very low absolute numbers of residents prescribed antipsychotics. It was felt that data collected would only really be of use for measuring improvements in individual care homes rather than making meaningful comparison between homes.

### **3.6 Electronic Medicines Administration Records (eMAR)**

In most care homes medicines administration records (MARs) are paper charts detailing, amongst other information, the name, form and strength of each prescribed medicine alongside directions for their appropriate administration. Because MARs in the majority of care homes are physical documents reviewing data is, in common with audit, time consuming and resource intensive.

In some care homes paper MAR charts have been replaced by electronic MAR (eMAR) systems. The Welsh Government has previously provided grant funding through its *Health Technology and Telehealth Fund (HTTF)* to support the evaluation of eMAR systems in care homes. An evaluation of eMAR use in care homes in Wales demonstrated improvements in patient safety and reductions in medicines waste and identified significant potential for such systems to monitor the prescribing and administration of certain classes of medicines including antipsychotics.<sup>12</sup>

### **3.7 Limitations of data**

Prescribing indicators are an important tool for stimulating quality improvement. Such indicators, no matter how sophisticated, cannot of themselves demonstrate good or poor practice.

Prescribing indicators can be successfully used to identify variation in significantly different prescribing to 'the norm'. Where indicators highlight such variation, further work is always needed both to quantify and qualify the appropriateness of practice.

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<sup>12</sup> Al-Hamadani F et al. Telehealth Enabled Medicines Management for Care Home Residents. Cardiff University. 2015. Available at: [https://www.cardiff.ac.uk/\\_data/assets/pdf\\_file/0009/193752/CUEvaluation.pdf](https://www.cardiff.ac.uk/_data/assets/pdf_file/0009/193752/CUEvaluation.pdf) [accessed 14 November 2018]

The short life working group did not support the isolated use of routine data including prescribing indicators, for performance management. However the group recognises they may form part of a comprehensive assessment of quality.

Data on prescribing for individual care homes specifically for older patients are not available. We have considered the range of data that are currently available and we can consider the use of anti-psychotic prescribing by GP practice. However there is not a straightforward way to identify either the antipsychotic dosage prescribed to individual patients or their diagnoses.

Estimates of low dose anti-psychotic prescribing have been developed using dosage assumptions informed by professional advice. However this does not accurately capture the precise dose given to any individual patient.

Whilst it is possible to determine an estimate of prescribing rates for individual care homes, for example using the POMSI measures, there is significant variation in the size of individual homes, with many having small (in a statistical sense) numbers of patients. The small numbers (sample sizes) would mean each estimate would be bounded by wide confidence intervals. This would mean that the data would need careful interpretation as many of those confidence intervals would overlap meaning they would not be statistically different from one another.

Considering these issues together the short life working group agreed that it would be most appropriate to measure the variations in anti-psychotic prescribing at a GP practice level, identifying those with higher prescribing rates. These practices could independently or with support from health boards, then undertake detailed audits to identify the appropriateness of antipsychotic prescribing. This would highlight qualified concerns about individual care homes.

## 4 Recommendations

1. Prescribing indicators are an important tool for stimulating quality improvement. They provide useful information regarding variation within systems and should be used as a source of intelligence to guide further investigation. They should not be used for performance management.
2. Given the resource implications associated with its completion, its point prevalence nature and its limitations for measuring continuous improvement, audit of antipsychotic use in care homes should be intelligence led.
3. Whenever antipsychotic use in care homes is audited, the national Clinical Effectiveness Prescribing Programme (CEPP) audit tool should be used and arrangements should be in place to allow audit data to be reported to a central database from which reports can be generated to facilitate comparative analysis and track progress over time.
4. The central reporting system should be accessible to care homes, GP practices and pharmacies. Only summary data should be available to health boards to discourage inappropriate intervention that would discourage audit and have a negative effect on improvement.
5. Restrictions in regard to utilising data contained within 2D barcoded prescriptions prevents us from fully understanding prescribing numbers by location, age and gender. These arrangements should be reviewed and a solution sought to enable the collection and review of all data contained in NHS prescriptions.
6. Once arrangements allowing prescription and demographic data to be linked are in place, a national indicator measuring the number of patients over 65 prescribed for more than six weeks should be developed and reported at GP practice level.
7. The national prescribing safety indicator measuring the use of antipsychotic medication in patients aged 65 or over should be adapted to also report the number of those patients who are resident in a care home as a percentage of all patients aged 65 or over.
8. An indicator should be developed in the Audit+ system which can be used as the basis for a real time practice report which identified patients aged 65 or over prescribed for greater than six weeks.

9. Arrangements should be put in place for all pharmacies providing services to care homes to report Patient Outcome Medicines Safety Indicators (POMSI) measures at least biannually.
10. Arrangements should be put in place to facilitate Electronic Medicines Administration Records (eMAR) systems which report to a central data repository being used in all care homes in Wales.

## 5 Conclusions

For some time there have been concerns regarding the overuse of antipsychotics where not clinically appropriate and, in particular, in care homes. There continues to be concern about the use of antipsychotic medicines being prescribed to control some of the behavioral symptoms of dementia.

When considering what measures might be put in place to substantiate and address these concerns, the short life working group identified a number of areas where data are routinely collected. The short life working group prioritised certain data in order to establish whether the volume of prescribing of antipsychotic medication in care homes was inappropriate. Data regarding the dispensing of antipsychotic medication; number of prescriptions; volume and type of medications are all readily identifiable and attributable to GP practice and dispensing pharmacy. However other relevant information, including the age and address of individual patients, whilst available cannot be utilised.

The short life working group consider the recommendations in this report represent a proportionate approach to measuring the scale of the problem and driving improvement given the constraints of the data currently available. The short life working group has made recommendations for relatively straightforward improvements to data collection which can be implemented promptly. Further work is required regarding the secondary use of prescription data but the short life working group strongly believe prescription data has significant potential in this and other situations.

## Annex One – Summary of literature review

Study	Year	Description of study	Setting	Measures
Ivers NM et al. Public reporting of antipsychotic prescribing in nursing homes: population-based interrupted time series analyses. <i>BMJ Qual Saf</i> Published Online First: 30 July 2018.	2018	Time series analysis	636 nursing homes in Ontario, Canada	% of residents with a prescription dispensed for any antipsychotic medication and % of residents with a prescription for benzodiazepine and/or trazodone
Carnaham RM et al. Impact of programs to reduce antipsychotic and anticholinergic use in nursing homes. <i>Alzheimer's and Dementia: Translational Research and Clinical Interventions</i> 2017; 3(4): 553-561	2017	Quasi-experimental longitudinal study comparing intervention and non-intervention homes	Nursing homes in Iowa USA	% of residents prescribed antipsychotics
Breining A et al. Exposure to psychotropics in the French older population living with dementia: a nationwide population-based study. <i>International Journal of Geriatric Psychiatry</i> 2017; 32(7): 750-760	2017	Prospective cohort study	Community and nursing homes in France	% of patients chronically exposed to antipsychotics (and other medicines) defined as at least three prescriptions per year
Frankenthal D et al. The impact of facility characteristics on the use of antipsychotic medications in nursing homes: a cross-sectional study. <i>Israel Journal of Health Policy Research</i> 2016 5:12	2016	Retrospective cross-sectional study	Nursing homes in Tel Aviv, Israel	% of residents prescribed antipsychotics
Mansbach WE et al. Predicting Off-Label Antipsychotic Medication Use in a Randomly Selected Nursing Home Sample Based on Resident and Facility Characteristics. <i>Research in gerontological nursing</i> 2016; 9(6): 257-266	2016	Observational study	Nursing homes	% of residents taking off-label antipsychotic medicines

Szczepura A et al. Antipsychotic prescribing in care homes before and after launch of a national dementia strategy: an observational study in English institutions over a 4-year period. <i>BMJ Open</i> 2016; 6:e009882.	2016	Retrospective analysis of prescribing patterns using information from electronic medicines management system	616 long term care institutions in England	% of residents prescribed antipsychotics
Backhouse T et al. Behavioural and psychological symptoms of dementia and their management in care homes within the East of England: a postal survey, <i>Aging &amp; mental health</i> 2014; 18(2): 187-193	2014	Postal survey	Care homes in four counties in East England	Number and % of residents prescribed at least one antipsychotic medication (regular and PRN prescriptions)
Foebal AD et al. Use of Antipsychotic Drugs Among Residents With Dementia in European Long-Term Care Facilities: Results From the SHELTER Study. <i>Journal of the American Medical Directors Association</i> 2014; 15(12) 911-917	2014	Cross-sectional, retrospective cohort	57 nursing homes in seven European countries and Israel	% of residents with dementia prescribed antipsychotic medication
Prentice A and Wright D. Reducing antipsychotic drugs in care homes. <i>Nursing Times</i> 2014; 110(23): 12-15	2014	Audit	463 care homes in Great Britain	Number and % of residents prescribed antipsychotic medication
Rapp MA et al. Agitation in Nursing Home Residents With Dementia (VIDEANT Trial): Effects of a Cluster-Randomized, Controlled, Guideline Implementation Trial. <i>Journal of the American Medical Directors Association</i> 2013; 14(9): 690-695	2013	Cluster randomized controlled trial	18 nursing homes in Berlin, Germany	Number of neuroleptics, antidepressants, and cholinesterase inhibitors (ChEIs) prescribed in defined daily dosages (DDDs)

Schultze J et al. Prescribing of antipsychotic drugs in patients with dementia: a comparison with age matched and sex matched non-demented controls. <i>Pharmacoepidemiology and Drug Safety</i> 2013; 22(12): 1308-1316	2013	Secondary analysis of health insurance claims data	Germany	% of patients with dementia prescribed antipsychotic medication
Richter T et al. Prevalence of psychotropic medication use among German and Austrian nursing home residents: A comparison of 3 cohorts. <i>JAMDA</i> 2012; 13(2): 187 e7-e187	2012	Cross-sectional comparison of data from 3 large studies performed between 2004 and 2007	136 nursing homes in Hamburg, Morin and Vorarlberg	% of residents with at least one prescription for psychotropic medication
Barro-Belaygues N et al. Patterns of dementia treatment use in assisted living facilities: A cross sectional study of 1975 demented residents. <i>JAMDA</i> 2011; 12(9): 648-654	2011	Cross sectional study	236 assisted learning facilities in France	% of residents prescribed cholinesterase-inhibitors also included % of residents prescribed concomitant antipsychotic medication
Wetzels RB et al. Prescribing pattern of psychotropic drugs in nursing home residents with dementia. <i>International psychogeriatrics</i> 2011; 23(8): 1249-1259	2011	Prospective cohort study	14 dementia special care units in 9 care homes in the Netherlands	% of residents prescribed antipsychotics

Annex two – Representatives and contributors

Andrew Evans (Chair)	Chief Pharmaceutical Officer, Welsh Government
Dr Elizabeth Davies	Senior Medical Officer Deputy Director Mental Health and Vulnerable Groups, Welsh Government
John Morris	Head of Health, Social Services and Population Statistics, Welsh Government
Andrea Giordano	Deputy Director Improvement, Welsh Government
Dr Andrew Havers	Senior Medical Officer for Primary Care, Welsh Government
Simon Scourfield	Primary Care Operations Management Lead - NHS Wales Informatics Service (NWIS)
Kath Haines	Head of Welsh Analytical Prescribing Support Unit - All Wales Therapeutics & Toxicology Centre (AWTTC)
Claire Thomas	Pharmacist - All Wales Therapeutics & Toxicology Centre (AWTTC)
Neil Jenkins	Head of Modernisation & Technical Services - NHS Wales Shared Services Partnership
James Goddard	NHS Wales Shared Services Partnership
Fiona Walker	Cardiff & Vale UHB, Primary, Community & Intermediate Care
Victoria Gimson	Specialist Mental Health Pharmacist - Cardiff & Vale UHB, Pharmacy
Karen May	Cardiff & Vale UHB – Pharmacy – Primary Care
Wendy Davies	Cardiff & Vale UHB – Pharmacy – Secondary care
Sarah Glynn-Jones	Head of Adult and Children's Services Inspection - Care Inspectorate Wales (CIW)
Louise Armstrong-Rodgers	Team Manager Adult Services Inspection - Care Inspectorate Wales (CIW)
Darren Ormond	Secretariat, Welsh Government

**Vaughan Gething AC/AM**  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

Agenda Item 2.2



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref MA-P-VG-3073-18

Dr Dai Lloyd  
Chair  
Health, Social Care and Sport Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

19 February 2019

Dear Dai,

You may recall that I wrote to you on 27 April 2018 in response to your letter of 21 March 2018 regarding the Health, Social Care and Sport Committee's one-day inquiry into the All Wales Medical Performers List on 7 March 2018.

In my letter to you of 27 April, I advised that I would keep you updated on any proposed changes to the Performers Lists following an analysis of the responses to the informal consultation on the NHS Wales Performers List. Accordingly, for information, please find attached the Government's response to the informal consultation which issued recently.

Yours sincerely,

**Vaughan Gething AC/AM**  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

Health and Social Services Group  
Y Grwp Iechyd a Gwasanaethau Cymdeithasol



Llywodraeth Cymru  
Welsh Government

Associate Medical Directors of Health Boards  
Medical Directors of Health Boards  
The Royal College of General Practitioners  
Prof Malcolm Lewis, Director of General Practice and Revalidation at the Wales Deanery  
Directors of Primary Care of Health Boards  
Chair, General Practitioners Committee Wales  
Chair, Welsh General Dental Practitioners Committee  
Chair, British Dental Association  
British Dental Association Wales National Director  
Director, Primary Care Services, NHS Wales Shared Services Partnership  
Local Community Health Councils  
Local Medical Committees  
Other Respondents to the Informal Consultation

Eich Cyf/Your Ref:  
Ein Cyf/Our Ref:

19 February 2019

Dear Colleagues

## **OPTIONS PAPER: NHS WALES PERFORMERS LIST**

I refer to the informal consultation on the above which issued on 29 November 2017 and closed on 8 February 2018. The purpose of the informal consultation was to identify measures to simplify the process for performers to perform primary medical and dental services in Wales.

### **Consultation Exercise**

Seven potential measures were presented as outlined below –

- Option 1 – Establish a UK or England/Wales Joint Performers List
- Option 2 – Establish a Single Wales Performers List
- Option 3 – Amend the current Regulations to allow a General Practitioner (GP) or General Dental Practitioner (GDP) Performer to be automatically listed on a LHB's List if they are already on a Primary Care Organisation's (PCO) performer list in England, Scotland or Northern Ireland, with no requirement to submit an application or provide relevant information and documentation



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- Option 4 - Amend the current regulations to allow a GP or GDP already listed on a PCO list who completes the current streamlined application form to be immediately listed on the LHB list after consideration by the LHB of the information provided in that application (within 5 working days) without the need for further information being requested from England i.e. references, professional experience and a DBS enhanced criminal records certificate.
- Option 5 – Amend the current regulations to extend the 3 month grace period to 6 months for a GP or GDP to be listed immediately with the LHB on receipt and consideration of their application whilst further checks are undertaken.
- Option 6 - Do nothing and continue with the current arrangements.
- Option 7 – Continue with the current arrangements but amend the Regulations to allow a GP or GDP Performer to provide their own clinical references, professional experience and medical qualifications with their application to the Welsh Performers List if they so wish.

### **Consultees' Response**

Twenty seven responses were received on the consultation presenting a number of differing views. Twenty three of those responses were from individuals/organisations in North Wales and therefore the responses to the consultation are not representative of Wales as a whole. However, this may suggest particular problems in the North Wales area.

Of the 23 responses received from North Wales, 16 people supported Option 3 but many of those 16 responses gave no commentary/evidence as to why Option 3 was the preferred option.

The other seven responses from North Wales included four supporting Option 1 with two of these wanting to implement Option 3 in the interim; one indicating their preference to be Options 1, 4 and 5; one supporting Option 4; and one supporting Option 6 and stating it would not support Options 3, 4, 5 and 7 on governance grounds.

Of the four respondents outside North Wales, one did not specify an Option but put forward a list of legislative changes which would go some way to reducing the bureaucracy inside existing arrangements; one supported Options 1, 2 and 3 with no particular preference; one supported option 2 with a number of observations; and one supported Option 7.

Having reviewed all the consultation responses and taking into account the written and oral evidence given to the Health, Social Care and Sport Committee the Welsh Government's view on each of the seven options are as follows –

### **Welsh Government's Response**

- Option 1 – Establish a UK or England/Wales Joint Performers List

Given the practical difficulties outlined in the Options Paper and the need for agreement from all the devolved administrations for a UK list, along with primary legislation, this option is not feasible at this time.

- Option 2 – Establish a Single Wales Performers List

A single list for Wales would require a change to primary legislation i.e. the NHS (Wales) Act 2006. It would also require organisational changes so that a single all-

Wales body would be responsible for managing and monitoring the performers list and so that the functions of the reference panels can be effectively carried out.

As the 2006 Act currently stands, performers need only be on one LHB list to work in any LHB area in Wales. This therefore already creates an “all-Wales” system which facilitates movement across the LHB boundaries.

- Option 3 – Amend the current Regulations to allow a GP or GDP Performer to be automatically listed on a LHB’s List if they are already on a PCO performer list, with no requirement to submit an application or provide relevant information and documentation.

Since the consultation a National Audit Office (NAO) report (published 17 May 2018) found that patients could potentially have been put at risk because of problems with Capita’s administration of the performers list in England. Delays in processing new applications and making changes to existing performers, including whether GPs, dentists and optometrists practising in the NHS were suitably qualified and had passed other relevant checks, resulted in potential risks to patient safety, especially in cases where performers should have been removed from a list.

Allowing a performer registered in England to be listed automatically in Wales could therefore compromise patient safety. This reinforces the importance of undertaking our own checks and balances on those performers who wish to perform in Wales. We will not be pursuing this option.

- Option 4 - Amend the current regulations to allow a GP or GDP already listed on a PCO list who completes the current streamlined application form to be immediately listed on the LHB list after consideration by the LHB of the information provided in that application (within 5 working days) without the need for further information being requested from England i.e. references, professional experience and a DBS enhanced criminal records certificate.

The same response applies here as for Option 3.

- Option 5 – Amend the current regulations to extend the 3 month grace period to 6 months for a GP or GDP to be listed immediately with the LHB on receipt and consideration of their application whilst further checks are undertaken.

Welsh Government officials have contacted NHS Wales Shared Services Partnership (NWSSP) and confirmed that 100% of performers who have submitted a completed application with the relevant documentation have been provisionally listed on the performers list within five working days. Those performers are then free to perform primary care services whilst the further checks are undertaken. Of those performers provisionally listed, 97% were fully included in the performers list within 3 months. NWSSP have confirmed that delays can occur when a performer’s application is incomplete.

Given these statistics, there is not a compelling argument to extend the grace period to 6 months.

- Option 6 - Do nothing and continue with the current arrangements.

This is not an option as the consultation exercise has highlighted that we can improve upon current arrangements. Accordingly, we will be considering changes to the current arrangements.

- Option 7 – Continue with the current arrangements but amend the Regulations to allow a GP or GDP Performer to provide their own clinical references, professional experience and medical qualifications with their application to the Welsh Performers List.

We have considered this option and believe that there may be further simplifications to the process of obtaining clinical references, professional experience and medical qualifications for performers already listed in another area and who wish to apply to a new area. This is detailed below.

## **Proposals**

### *Reassignment of performers*

It is recognised that the requirement for a new application when an applicant moves from one LHB area in Wales to another increases the administrative burdens on performers. We will therefore pursue the possibility of providing a system of transfer or reassignment where a performer moves to a new LHB, subject to appropriate safeguards, to minimise burdens and delay. The details will be considered further.

### *Provision of references, professional experience and qualifications*

We believe that the application process could be streamlined by allowing an existing performer to provide either (i) the names and addresses of two clinical referees and updated professional experience and medical or dental qualifications; or (ii) their consent for the LHB to obtain previous clinical references, professional experience and qualifications from the PCO where the performer is currently listed. Alternatively the applicant could provide both (i) and (ii).

### *North Wales*

The consultation exercise has highlighted difficulties in North Wales. The position in North Wales will be kept under review and if difficulties continue, consideration will be given to identify any measures that could be put in place to ease the situation.

In addition, we have considered the list of legislative changes provided by one respondent and will amend the Regulations where appropriate, to take account of them to assist in reducing the bureaucracy in existing arrangements.

Yours sincerely



**Karin Philips**

**Deputy Director: Primary Care  
Primary Care Division**

Vaughan Gething AC/AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

Agenda Item 2.3  


Ein cyf/Our ref MA-P/VG/0346/19

Llywodraeth Cymru  
Welsh Government

Dr Dai Lloyd AM  
Chair, Health, Social Care and Sport Committee  
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19 February 2019

Dear Dai,

Thank you for your letter of 18 January 2019 regarding the HSCS Committee evidence session on the cross-party group inquiry into inequalities in access to hospices and palliative care. I will respond to your points in the order you have raised them.

### Data Collection

Capturing data at such a sensitive time in people's lives is never going to be easy. However, I do acknowledge that there are gaps in end of life care data collection in Wales and we are working closely with NWIS and the End of Life Care Board to improve the quality of data collected. This includes:

- Considering the future for CANISC, the data collection tool used for end of life care in Wales. Design and implementation of functionality to replace CANISC will provide an opportunity to collect information in the course of documenting the care provided to patients, as well as enhancing the ability to extract this information for secondary uses. It is expected that when this functionality is available, there would be both additional, and more accurate information available about the care that is provided by Wales' Specialist Palliative Care Teams.
- Using the VOICES in Wales pilot project to explore the feasibility of implementing a national survey of bereaved carers by incorporating initial data collection, and invitation and consent to participate, with the process of death registration and the new Medical Examiners' Service.
- Supporting health boards to participate in the National Audit of Care at the End of Life (NACEL) which focuses on the quality and outcomes of care experienced by those in their last admission in acute, community and mental health hospitals throughout England and Wales. This includes a case note review of inpatients in hospital in the last few days and hours of life and an organisational level audit covering service models, activity, workforce, finance quality and outcomes. Both carer and staff views have also been captured for the first time in this audit and we

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

will work closely with health boards to ensure that the recommendations are taken forward in a timely manner. We will also be providing feedback to NHS Benchmarking, the provider responsible for delivering the audit to improve the quality of future audits and to ensure that they more adequately reflect Welsh structures. The National Summary report for England and Wales is scheduled to be published on 22 May 2019.

## **GP Palliative Care Registers**

In relation to the benefit of palliative care registers, you are right in your suggestion that being placed on the register serves as a trigger for an appropriate set of actions from the primary care team and for onward referral for relevant support. These actions might include but are not limited to: more frequent reassessment by GP or district nurse; benefits advice; advance care planning; discussion of preferred place of care or other preferences. They are not specific as they will be tailored to individual need. However, the common thread is the identification of need and the timely response to it.

The CPG also questioned the value of palliative care registers and the End of Life Care Board is currently considering what measures it can take to monitor their effectiveness including discussing with academics whether a piece of research could be commissioned.

In terms of seeking assurance that patients are consulted prior to being placed on a palliative care register, this information is only being used and disclosed for direct care so would be covered by existing GP information sharing arrangements, unless it involved sharing information outside of the healthcare team in which case, additional patient consent would be sought.

## **Pooled Budgets**

In terms of progressing pooled budgets with pace, we have recently consulted on draft amendment regulations to:

- Part 9 of the Social Services and Well-being Act 2014, in order to: Provide additional clarity that all local authorities and the health board within a partnership must contribute to the establishment of a single regional pooled fund;
- Specify the focus of pooled funds is limited to care home accommodation for older people.

The consultation closed in October 2018 and officials are in the process of preparing full advice on the consultation responses received.

Additionally, to promote the establishment of pooled funds the Welsh Government had commissioned the Institute of Public Care (IPC) at Oxford Brookes University to undertake an independent review of pooled funds. The independent review supported the potential benefits of pooled funds between local authorities and health organisations and highlighted ways they could help to improve people's wellbeing. Furthermore, the Welsh Government has commissioned Association of Directors of Social Services (ADSS) Cymru to develop a range of practical tools to support regional partnerships.

## **Bereavement support**

The study to identify and gather information on structured bereavement services available in Wales is progressing well. Marie Curie Palliative Research Centre are undertaking this work and have conducted a literature review to identify key themes and questions used in previous bereavement scoping exercises and evaluations to aid development of a bereavement survey. The survey has been amended following peer review and is now being tested with key stakeholders within the field of bereavement support prior to being finalised. It is anticipated that the survey will go live in February 2019 and run for a period of up to 8 weeks. An interim report is expected in the spring, with the final report expected in the autumn.

With regards to carer representation on the Ministerial Advisory Group, I can confirm that a small group has been tasked with developing proposals for how the Engagement and Accountability Group will work with the Ministerial Advisory Group. We expect a paper outlining the relationship between the two groups to be brought to the next meeting of the Engagement and Accountability Group, likely to be April or May. As officials have previously discussed with Catrin Edwards, we remain committed to including a representative of the needs of carers for those at the end of life on the Engagement and Accountability Group.

## **District Nursing**

Thank you for the information on your plans to conduct a short inquiry into community and district nursing. Our approach in 'A Healthier Wales', is about access to the right care at the right time from the right source of help at or close to home. Through our Primary Care Model for Wales, which supports the vision set out in A Healthier Wales, the Welsh Government is committed to investing in the wider primary care team, including district nurses who provide the core universal nursing care service at home.

I would also like to inform you that my officials have written to health board Chief Executives and asked them to set out how they intend to address the specific recommendations for health boards within the Cross-Party Group Report. My officials will continue to monitor progress on these and all the other recommendations in the report.

Yours sincerely,



**Vaughan Gething AC/AM**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

Vaughan Gething AM  
Minister for Health and Social Services

18 January 2019

Dear Vaughan

At its meeting on 13 December 2018, the Health, Social Care and Sport Committee held an evidence session with members of the Hospice and Palliative Care Cross-party Group (CPG) to discuss the findings of its report *'Inequalities in access to hospice and palliative care: challenges and opportunities'*.

After the session, Members asked that I write to you highlighting the following areas of concern:

### **Data collection**

The CPG reported difficulties in collecting and coordinating data on palliative care use, both for adult and paediatric services. While individual patient level data on specialist palliative care use is recorded, which can provide insight into the number of specialist palliative care services provided at health board and national levels, it cannot provide an accurate figure of the number of people receiving specialist palliative care as many people will access more than one service, including from different providers.

We note that, in accepting Recommendation 9 of the CPG report, you have given a commitment to continue to routinely review data collection mechanisms and take action to improve systems for identify gaps in data *as and when opportunities arise*. However, given the importance of robust data in planning future service provision, we would urge you to increase the priority given to this work.

### **GP Palliative Care Registers**

We note the CPG recommendation that the Welsh Government and End of Life Care Implementation Board should establish a target for increasing the number of people on General Practice Palliative Care Registers and introduce measures to monitor their effectiveness in supporting adults with all life-limiting conditions.



However, in their evidence to Committee, representatives of the CPG told us that they were unclear what it means for people who are put on the register – is this a trigger for them to be referred to appropriate services or to receive appropriate services through their GP. We would therefore appreciate clarification on the benefits to the patient of being included on the GP register.

Further, we would seek assurance that patients are fully consulted prior to their inclusion on the register.

### **Pooled budgets**

Recommendation 5 of the CPG report states that Regional Partnership Boards should make use of pooled budgets to support the delivery of palliative care in care homes.

In accepting this recommendation, you say that this is something that already happens to a certain extent as regulations made under Part 9 of the Social Services and Well-being Wales (Act) 2016 require that regional partnership boards established pooled funds in relation to their care home accommodation functions from April 2018. The Welsh Government would expect therefore that these pooled funds would already include meeting the costs of any identified palliative care costs when care is commissioned.

However, representatives of the CPG told us it would appear that this is slow in progressing, and regional partnership boards are only just beginning to think in terms of pooled budgets. We would therefore ask you to ensure regional partnership boards progress this with pace.

### **Bereavement support**

The CPG report highlights the necessity of appropriate bereavement support (including pre-bereavement support) for families and carers through and beyond their caring journeys. Despite the importance of this service to those affected by death and dying, the CPG told us of cut backs in bereavement support, particularly specialist bereavement counselling, from both the statutory and third sectors. Hospices continue to offer this vital service but report increased pressure on the services they provide in response to service closures elsewhere.

Your response to Recommendation 6 of the CPG – *The Welsh Government Ministerial Advisory Group for Carers should address the specific support needed by carers of people at the end of life* – states that Welsh Government officials met Catrin Edwards of Hospice UK on 17 July and discussed how the interests of carers of people at the end of life could be represented in the Engagement and Accountability Group.



We would appreciate an update on this work.

### **Community nursing**

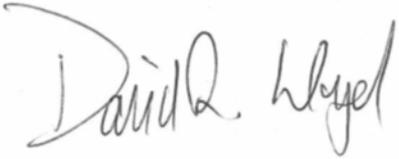
The CPG report highlights issues around workforce pressures – specifically shortages of GPs, district nurses and community paediatric nurses who coordinate and deliver the day-to-day care of people with palliative care needs in the community.

In evidence to the Committee, representatives of the CPG told us that “district nursing is absolutely the bedrock of care for people at home and if there was one thing that we could change that would make a massive difference for people to be cared for at home for as long as possible, it’s investment in district nursing.”

In light of this, and representation we have received from the Cross-Party Group on Nursing and Midwifery, the Committee has agreed to undertake a short inquiry into community and district nursing.

I look forward to receiving your response to the issues raised above in due course.

Kind regards



Dr Dai Lloyd AM  
**Chair, Health, Social Care and Sport Committee**



**Vaughan Gething AC/AM**  
**Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol**  
**Minister for Health and Social Services**

# Agenda Item 2.4



Ein cyf / Our ref: MA-L/VG/0239/19

Llywodraeth Cymru  
Welsh Government

Dr Dai Lloyd AM  
Chair  
Health, Social Care and Sport Committee  
National Assembly for Wales  
Cardiff Bay  
CF99 1NA

28 February 2019

Dear Dai,

Following my letter to Stephen Hammond MP of 12 February 2019, the UK Government has agreed to the additional wording I requested be included in the Memorandum of Understanding to underpin the Healthcare (International Arrangements) Bill. An amendment to the Bill to place a requirement to consult devolved administrations will be made at Lords Report Stage. On that basis, I am content to recommend that the National Assembly provides consent to the Bill.

The MoU now sets out:

- That Welsh Government will be consulted on the negotiation of agreements, with a role from the initial scoping through to the conclusion of a draft agreement;
- That Welsh Government will be consulted on the initial development and subsequent drafting of regulations under the Bill which implement these agreements, with the UK Government making every effort to proceed by consensus with the devolved administrations;
- That Welsh Government will be consulted where an agreement applies to or has implications for Wales, and on regulations giving effect to that agreement;
- That the UK Government will not normally make regulations without securing agreement from Devolved Administration Ministers beforehand;
- A process for exchanging Ministerial letters in the event of Devolved Administration agreement not being reached where regulations under Clause 2 intersect with devolved competence; and
- That these letters be made available to both Houses of Parliament in the event that the regulations proceed to be made by the Secretary of State for Health and Social Care.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

These assurances give Welsh Government a meaningful role in the development of future reciprocal healthcare policy. I am attaching a copy of the agreed Memorandum of Understanding.

I would like to restate my thanks for the work the Committee has done on this issue, and hope you agree with me that this represents a positive development in this policy area.

Yours sincerely,

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive, flowing style.

**Vaughan Gething AC/AM**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

# Healthcare (International Arrangements) Bill

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AMENDMENTS  
TO BE MOVED  
AT REPORT

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**After Clause 4**

BARONESS BLACKWOOD

Insert the following new Clause—

**“Requirement for consultation with devolved authorities**

- (1) Before making regulations under section 2 that contain provision which is within the legislative competence of a devolved legislature, the Secretary of State must consult the relevant devolved authority on that provision.
- (2) In this section—
  - “devolved authority” means the Scottish Ministers, the Welsh Ministers or a Northern Ireland department;
  - “devolved legislature” means the Scottish Parliament, the National Assembly for Wales or the Northern Ireland Assembly.
- (3) A provision is within the legislative competence of a devolved legislature if—
  - (a) it would be within the legislative competence of the Scottish Parliament if it were contained in an Act of the Scottish Parliament;
  - (b) it would be within the legislative competence of the National Assembly for Wales if it were contained in an Act of the Assembly (including any provision that could only be made with the consent of a Minister of the Crown); or
  - (c) the provision, if it were contained in an Act of the Northern Ireland Assembly—
    - (i) would be within the legislative competence of the Assembly, and
    - (ii) would not require the consent of the Secretary of State.”

## ANNEX 2

### MEMORANDUM OF UNDERSTANDING FOR CONSULTATION UNDER SECTION 5 OF THE HEALTHCARE (INTERNATIONAL ARRANGEMENTS) ACT

#### A. Introduction and overarching principles

1. This Memorandum of Understanding sets out the arrangements agreed between the Department of Health and Social Care (“DHSC”) and the devolved administrations to support meaningful consultation in line with Section 5 of the Healthcare (International Arrangements) Act (“HIA Act”). DHSC recognises that the devolved administrations have a significant role to play where arrangements to facilitate treatment outside the UK and implement healthcare agreements relate to devolved matters.
2. The UK Government and the devolved administrations are committed to delivering a reciprocal healthcare policy that works for all parts of the UK. DHSC will work with the devolved administrations, involving the Territorial Offices as appropriate, to achieve this objective.
3. The UK Government and devolved administrations will make every effort to proceed on the basis of consensus in order to achieve a consistent reciprocal healthcare system.
4. Section 5 of HIA Act requires the Secretary of State to consult the relevant devolved authority before making regulations under clause 2 that contain provision within the legislative competence of a devolved legislature.
5. Section B of this Memorandum of Understanding is not limited to consultation in line with Section 5 of HIA Act. Section C relates to the consultation requirement in Section 5 of HIA Act.
6. The arrangements set out in this Memorandum of Understanding will be underpinned by regular engagement between DHSC’s and the devolved administrations’ officials, which will support Ministerial engagement. It is acknowledged that these arrangements will rely for their effectiveness on mutual respect for the confidentiality of information exchanged.
7. This Memorandum of Understanding as far as it relates to reciprocal healthcare agreements, will apply where DHSC is the lead UK government department negotiating such an agreement. The principles of this Memorandum of Understanding will also apply to healthcare agreements which do not require the Secretary of State to make regulations under Section 2 of the Act. This Memorandum of Understanding is not legally binding and the arrangements it sets out do not extend the statutory consultation duty in Section 5 of HIA Act.
8. This Memorandum of Understanding does not affect any healthcare agreements or arrangements entered into and/or to be entered into by a Minister of the Northern Ireland Executive with the Republic of Ireland.<sup>1</sup>

#### B. Policy Formation and Negotiations

9. DHSC will discuss with DA officials its policy proposals on the strategic direction for new reciprocal healthcare arrangements and any projected quantitative impact assessments of those proposals. Such engagement will occur as soon as possible at a formative stage of policy development. DHSC

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<sup>1</sup> In accordance with participation in the North South Ministerial Council, the British Irish Council or in relation to the activities of North South Implementation Bodies established on the basis of Strand Two of the Belfast Agreement.

## **ANNEX 2**

Ministers will write to DA Ministers to set out the policy proposals they endorse in order to build consensus on the direction to be taken in negotiations. Sharing this policy does not bind UK Government decisions.

10. To support policy formation, the devolved administrations will provide DHSC with timely comments on the documents shared and any relevant information or analysis to inform DHSC's evaluations of existing arrangements and its projected impact assessments.
11. DHSC will seek the devolved administrations' input on its negotiating positions for new healthcare agreements insofar as they relate to matters within devolved competence. DHSC Ministers and DA Ministers should be prepared for short notice intergovernmental engagement to meet international deadlines.
12. DHSC will discuss any model agreements or initial drafts of agreements drafted by DHSC with the devolved administrations before they are shared with third countries.
13. DHSC will provide updates to the devolved administrations on the progress of negotiations.
14. DHSC will share relevant information pertaining to an agreement, once it has been reached, with the devolved administrations, to ensure appropriate and successful implementation.
15. DHSC officials will notify the DA officials as early as possible should any of its policy proposals or any healthcare agreements require the Secretary of State to make regulations under Section 2 of the Act and set out its reasons.
16. DHSC will discuss any proposals for the review or amendment of implemented healthcare agreements with the devolved administrations in accordance with the arrangements set out above. The devolved administrations will provide DHSC with timely comments and relevant data, information and analysis to inform reviews.

### **C. Drafting of Regulations under Section 2 of HIA Act**

17. DHSC officials will share draft versions of any regulations to which Section 5 applies with devolved administrations prior to finalisation to provide the opportunity to discuss the content and drafting of the provisions that would be within the legislative competence of a devolved legislature.
18. A final draft of the regulations to which Section 5 applies, will be shared with the relevant DA Ministers as early as possible and before they are laid.
19. UK Government will make every effort in the making of regulations to which Section 5 of HIA Act applies to proceed on the basis of consensus and will not normally make regulations that have not been agreed with Ministers from the devolved administrations.
20. In the event that agreement cannot be reached, there will be an exchange of letters between Ministers. This would provide the opportunity for a devolved administration to set out its position, and for the Secretary of State to explain the reasons for the final form of the regulations and how the UK Government has sought to reach agreement. If the Secretary of State decides to proceed with making the regulations, and guided by the principles of the Intergovernmental Agreement, the exchange of letters should be made available to both Houses of Parliament when the regulations are laid.

## **ANNEX 2**

### **D. Regulations made by the Devolved Administrations**

21. The application of the principles in Section B of this Memorandum of Understanding will ensure that the devolved administrations are aware of any complementary regulations that will have to be made alongside the regulations made by the Secretary of State under Section 2 of HIA Act. Accordingly, the devolved administrations will make the required necessary legislative changes to ensure that there is a consistent reciprocal healthcare system.
22. To ensure UK-wide consistency where possible, the devolved administrations officials will discuss with DHSC officials the content and drafting of any regulations they intend to make to implement a reciprocal healthcare agreement as early as practicable before the regulations are laid.

### **E. Operational Implementation**

23. DHSC officials will liaise with the DA officials to ensure that the operational implementation of reciprocal healthcare policy works for all parts of the UK. This may for example include developing and coordinating bespoke packages of communications to inform individuals and healthcare providers about new reciprocal healthcare agreements.

### **F. Review**

24. This Memorandum of Understanding will be reviewed within 24 months of the date it is agreed, with any subsequent reviews to be scheduled in the course of the review. This review will be conducted by officials and agreed by Ministers.



Ein cyf/Our ref: MA - L/VG/0239/19

Stephen Hammond MP  
Minister of State for Health  
Department of Health and Social Care  
39 Victoria Street  
London  
SW1H 0EU

28 February 2019

Dear Stephen,

## **HEALTHCARE (INTERNATIONAL ARRANGEMENTS) BILL**

Thank you for your letters of 20 and 27 February notifying me that the proposed additional wording to the Memorandum of Understanding to underpin the intended amendment to the Healthcare (International Arrangements) Bill has been agreed.

I welcome this confirmation and wish to take the opportunity to echo your recognition of the positive working relationships between your Department and the Welsh Government which has enabled us to reach this position. I very much look forward to this approach continuing in relation to the development of healthcare agreements and any regulations giving effect to these agreements.

In the light of the agreement on the proposed amendment to the Bill and the MoU, I can confirm that arrangements are in hand for a Supplementary Legislative Consent Memorandum and Motion to be laid which will recommend that the National Assembly gives consent to the Bill. The Supplementary Legislative Consent Memorandum is due to be laid on 1 March 2019 and the debate on the Motion is scheduled for 12 March 2019. My officials will notify your Department of the outcome of the debate.

I would note that any statutory instrument which amends Welsh primary legislation would of course be subject to a Statutory Instrument Consent Motion in the Assembly, and it would be for the National Assembly for Wales to decide whether to recommend that consent be given.

I am copying this letter to the First Minister, the Scottish Government Cabinet Secretary for Health and Sport, the Northern Ireland Permanent Secretary for the Department for Health, the Secretary of State for Wales and the Chancellor of the Duchy of Lancaster and Minister for the Cabinet Office.

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We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

Yours sincerely,

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive, flowing style.

**Vaughan Gething AC/AM**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



**Department  
of Health &  
Social Care**

*Stephen Hammond MP  
Minister of State for Health*

*39 Victoria Street  
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*020 7210 4850*

Vaughan Gething AM  
Minister for Health and Social Services  
5th Floor, Tŷ Hywel  
Cardiff Bay CF99 1NA

**27 FEB 2019**

*Dear Vaughan,*

**HEALTHCARE (INTERNATIONAL ARRANGEMENTS) BILL**

I would like to reiterate my gratitude for your continued positive engagement with both myself and at official level in relation to the Healthcare (International Arrangements) Bill.

I am writing to assist with the Welsh Assembly's legislative consent process by confirming that the Government will be tabling an amendment to the Bill for Report Stage in the House of Lords on 12 March 2019.

As we have previously discussed, this amendment will place a statutory duty on the UK Government to consult the Devolved Administrations (DAs) where regulations under Clause 2 of the Bill would be within the DA's legislative competence. A Memorandum of Understanding (MoU) will underpin the amendment to the Bill, as agreed between the UK and Welsh Government. For ease of reference, I have attached these two documents as annexes.

The Government is committed to ensuring that arrangements will be conducive to the development of a reciprocal healthcare system that operates effectively across the whole of the UK and I look forward to continuing to work closely with you and at official level to achieve this.

I am copying this letter to the Scottish Government Cabinet Secretary for Health and Sport and the Northern Ireland Permanent Secretary for the Department of Health.

*with best wishes*

**STEPHEN HAMMOND**

Vaughan Gething AC/AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

Agenda Item 2.5



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref: MA-P/VG/0486/19  
Dr Dai Lloyd AM  
Chair  
Health, Social Care and Sport Committee  
National Assembly for Wales  
Cardiff Bay  
CF99 1NA

22 February 2019

Dear Dai,

Thank you for your letter of 25 January regarding the implementation of the Nurse Staffing Levels (Wales) Act 2016. As you have highlighted, the health boards are not required to report on the implementation of the Act until April 2021. However, through review and monitoring of the regular papers submitted to the health boards and through close working with the All Wales Nurse Staffing Group, my officials are kept broadly informed of the Act's implementation thus far and issues as they arise.

### **Implementation of the Act**

Wales is the first country in Europe to have passed legislation of this kind, meaning there is no established roadmap to implementation. We are therefore working through each challenge as it arises, learning as we go, and using a collaborative approach between Welsh Government and the health boards. Clearly the duties of the Act are placed on individual health boards/trusts and it is for them to deliver on the legislative requirements. As distinct organisations it would be unsurprising to find some minor local variation in how the legislation has been implemented. However, through the statutory guidance, operational guidance and the national engagement through the All Wales Nurse Staffing Group, a once-for-Wales approach has been adopted and applied wherever possible. This is fundamental in the essential areas where the Act leaves no room for interpretation, for example: the specific method of calculation; the need to inform patients; and the roles and responsibilities of health board staff within the process.

All health boards have completed the necessary triangulated calculations and recalculations for their wards that come under the duty of sections 25B and C, and all but one can demonstrate that they are taking all reasonable steps to maintain those calculations.

Part of the rationale behind the Act is to ensure the NHS more widely recognises the professional judgement of nurses in identifying the holistic needs of their patients and to enable nurses from ward to board level to have the necessary and sometimes difficult conversations about the resource requirements to meet those identified needs. We already hear anecdotally through the various supporting group meetings that this is happening right

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We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

up to executive level, and I would anticipate that to be reflected more formally in the three year report.

### Compliance in Cwm Taf

As I set out in my written statement of 9 January on Cwm Taf University Health Board's raised escalation status, they have been the sole outlier in terms of non-compliance with the Act thus far. It might be helpful if I provide more detail of the nature of the issue, which only came fully to light upon the publishing of the health board's meeting papers at the end of November last year. The Act states that there is a duty on health boards to calculate nurse staffing levels for their acute adult medical and surgical wards using the triangulated methodology prescribed in the statutory guidance and to take *all reasonable steps* to ensure those calculated staffing levels are maintained. In Cwm Taf's case, although the executive nurse director and nursing hierarchy had undertaken the triangulated calculations, the necessary additional funding for staff was not supported by the board. This was a clear failure in their duty to take all reasonable steps to maintain the nurse staffing level. Upon identifying the issue, my officials immediately escalated the concern, helped to inform the decision to raise Cwm Taf's status to enhanced monitoring.

The Chief Nursing Officer wrote to the health board's Chief Executive on 20 December, once the situation had been clarified, outlining the immediate steps necessary to rectify the lack of compliance with the Act. I'm pleased to be able to inform you that the nurse staffing level calculations were presented to the board again at the January board meeting and the £4.5m additional funding originally identified as being needed to support compliance has now been allocated. This is a big step toward compliance. We will continue to monitor the health board's progress over the coming months as they ensure all reasonable steps are taken to maintain those calculations.

### Sustainable supply of nurses

The Welsh Government is committed to actively supporting health boards and trusts to meet the needs of the Act and understand what sufficient staffing looks like. We will continue to work with health boards & trusts across Wales on approving IMTPs, recognising that our workforce underpins services.

However, it is a reality that there is a shortage of registered nurses not only here in Wales and the UK, but internationally a majority of countries report shortages in registered nursing staff. The Assembly was aware of this when it unanimously passed the legislation with cross party support. We therefore have a responsibility to ensure that we are strategically coordinated at a national level in producing a sustainable supply of nursing staff for the future, attracting nurses to work in Wales and seeking ways to retain the nursing staff we have in the health and social care systems.

We are in a better position than ever to achieve this having established Health Education and Improvement Wales (HEIW) in October 2018. By amalgamating the Wales Deanery, NHS Wales's Workforce Education and Development Services (WEDS), and the Wales Centre for Pharmacy Professional Education (WCPPE), HEIW ensures that the people and healthcare professionals of Wales benefit from a cohesive, consistent approach to education and training, and to workforce modernisation and planning. A key objective of HEIW is to take a more strategic approach to future planning of the workforce and the alignment of the components needed to deliver it (education, training, role development, career pathways, continuous professional development etc). We will work in close partnership with HEIW in delivering this objective. The organisation has already been

engaged by the All Wales Nurse Staffing Programme to ensure that the implications of the Act are built in to their planning.

On top of this, we continue to increase the level of investment in the future workforce of NHS Wales. On 29 November 2018 I announced that £114m will be invested in 2019/20, an increase of £7m available in 2018/19 to support a range of education and training programmes for healthcare professionals in Wales. Our record of support for education and training, especially in terms of investment made in nurse education illustrates the importance we place on nursing staff. Since 2014, nurse training places have risen by 68% across all four fields of nursing. Looking specifically at areas where extension of the Act is being explored, health visitor training places have increased by 88% and district nurse training places by 233%.

We have also maintained the full bursary package for students starting their studies in September 2019 and we have consulted on options for longer term arrangements to support students. I will be announcing future healthcare student support arrangements in the near future. The full bursary package is currently available for those who commit in advance to work in Wales for up to two years post qualification. We provide support for staff to return to practice with funding up to £1,500 and we have retire-and-return schemes which enable us to retain the experience these staff members have.

Building on the marketing activity of the Train Work Live campaign, NHS Wales nurse and workforce leads, working alongside Welsh Government, are developing a once for Wales approach to international recruitment for registered nurses. Later this year Train Work Live for nurses will enter into its third year, with further marketing activity to support local recruitment, including a collective NHS Wales presence at major nursing conferences, eg RCN Congress in Liverpool in May.

### **Agency nurse spend**

With regard to agency costs, it would be safe to assume that a piece of legislation which will potentially require more nurses in a time of global shortage will have a direct impact on agency spend. However, having the appropriate number of registered nurses based on patient need is proven to reduce morbidity and improve patient outcomes and at times, the only way to achieve that in a certain circumstance is to employ agency staff. The Welsh Government is committed to working in partnership with NHS Wales to find practical and safe solutions to ensure we achieve a sustainable employed workforce supported by temporary workers.

Recruiting agency staff is explicitly listed in the Act as a temporary, reasonable step to ensuring patients receive the care they need. Over time we expect to reduce the need for agency staff through training and retaining more nurses.

The NHS Wales Shared Services Partnership hosts the All Wales Nursing Workforce Supply Group which provides a national, strategic lead on bank and agency nurse spend. Their key objectives include reducing agency expenditure and ensuring the further development of nurse bank capacity to meet the needs of NHS Wales. This group has been successful in introducing single All Wales capped rates for agencies and we now have around 98% of agency nurses supplied by approved contract agencies. They are currently looking at an All Wales approach to overseas recruitment but are also looking at internal recruitment and retention and gathering data on vacancies and the impact this has on bank & agency usage. In addition, the group is overseeing the implementation of an All Wales Bank. We have also introduced a new control framework for medical agency expenditure and as a result the agency expenditure on nurse and medical staff has reduced by some

£30 million in 12 months. Our ultimate aim would be to establish a single national framework for all temporary staffing in NHS Wales, and I am eager to see further progress towards that in this government term.

### **Extension into additional settings**

The wording of the Act and statutory guidance is quite clear about what is required to enable the extension of section 25B into other healthcare settings. As set out in the Act, an evidence-based workforce planning tool must be used in conjunction with professional judgement and quality indicators which are particularly sensitive to care provided by a nurse as part of a triangulated method of calculating nurse staffing levels. The evidence-based tool comprises both the acuity tool element (the Welsh Levels of Care in adult acute medical and surgical settings) and the platform and associated ICT infrastructure necessary to enable nurses to use that acuity tool.

The All Wales Nurse Staffing Group hosts five individual work-streams exploring the extension or implementation of the Act into different nurse settings, each being led by an executive nurse director as a sponsor, and a senior nurse of the respective setting as a chair. The work streams were established at different points in time over the last six years and are at varying stages of progress.

### **Paediatrics**

The paediatrics work-stream is objectively the most advanced in terms of developing the various components of an evidence based workforce planning tool. Given the similarities of the inpatient ward environment of paediatrics and adult medical and surgical wards, the work-stream was able to build upon the existing adult work and develop a Welsh Levels of Care (WLoC) acuity standard relatively quickly. There is also an established platform for data capture on paediatric inpatient wards meaning there is less work to be done than in other settings in terms of developing ICT infrastructure. I agreed funding in 2017 for a specialist project lead for the work-stream to accelerate the testing of the tool. That lead has been in post since January 2018, driving the iterative development of the WLoC and engaging with every paediatric ward in Wales in preparation for extension of the Act. It is currently expected that the development of that workforce planning tool will be completed within this government term.

### **District Nursing**

Significant progress has been made within the district nursing work stream in the last year. The interim CNO staffing principles for district nursing were published in September 2017 and health boards will be undertaking their third returns against compliance with those principles in March. This data has given us an invaluable view of the landscape of the workforce in this setting which will be vital in eventually calculating the impact the Act might have when extended to district nursing.

A draft WLoC for district nursing has been developed to the point where it now requires the same iterative testing in the field as was undertaken in adult acute medical and surgical wards and is ongoing in paediatrics. To ensure a consistent approach to the work, I have agreed to fund a project lead for district nursing following the model established in the paediatrics work stream. An open recruitment process was undertaken by the All Wales Nurse Staffing Programme - hosted within Public Health Wales – and an appointment has been made. It is anticipated that the successful candidate will begin in post in early April.

Unlike in the ward settings of adult acute medical and surgical and paediatric inpatients, there is not currently an established platform or standardised mobilisation in our community settings. This means that the district nursing project lead will also have to coordinate and drive the development of the suitable ICT infrastructure in parallel to developing the WLoC. I am unable to provide an exact timescale for that work, and any estimate at this stage would be arbitrary. Naturally, as the work progresses and the complexities are better understood, a reliable timescale can be formed.

### Health Visiting

A national health visitor work-stream staffing event was held on 14 January to commence discussions around exploring how the existing *universal/enhanced/intensive* scoring system could be adapted to inform a WLoC for health visiting. Unsurprisingly, with health visiting also being set in the community, this work-stream will face the same ICT infrastructure issues as district nursing. However, under the coordination of the All Wales Programme, I would expect any solution developed for the district nursing setting to also be applicable or adaptable for health visiting.

As Early Years was one of the key themes identified within our Prosperity For All strategy, Welsh Government has been working across education, health and social care to ensure we are taking a coordinated approach to families and children. As part of this cross-governmental work, health visiting was identified as a core component and a bespoke project has been undertaken to set out the model for future health visiting services. This work will play a critical role in informing future workforce requirements and the development of the WLoC tool in this setting. A set of draft interim staffing principles are in development that will reflect the future health visiting model.

### Mental Health In-patient areas

The mental health work-stream faces unique complexities in devising an evidence-based workforce planning tool as it must take into account not only the existing mental health levels of engagement and observation but also the acuity levels of physical care, which can vary greatly between different types of in-patient areas. Work is underway in understanding how those two elements will intersect and translate into WLoC for mental health and how this information will relate to nurse staffing levels. A national mental health work-stream event is planned for March to progress that work further, and draft interim staffing principles are in development.

### Care Homes

Section 25A of the Act came into force in April of 2017 and places a duty on all health boards and trusts to have regard to providing sufficient nurses to care for patients sensitively in any area where nursing services are contracted or commissioned. The care homes work-stream is focusing on consolidating a standardised methodology to support health boards in their care home commissioning responsibilities under the Act. The National Collaborative Commissioning Unit is supporting the progression of this work.

Again, to give estimated detailed timescales for developing these strands of work at this point would be unwise and potentially highly inaccurate. The Welsh Government is monitoring the progress of these different work-streams through my officials' involvement with the All Wales Nurse Staffing group. Preliminary discussions on where else the Act should be applied have begun to help shape the future national work programme. I will periodically inform the Committee and my Assembly colleagues of notable developments and detailed timescales as they emerge.

I hope you find my response helpful.

Yours sincerely,

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive, flowing style.

**Vaughan Gething AC/AM**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

**Carers Trust Wales  
33 - 35 Cathedral Road  
Cardiff  
CF11 9HB**

**26 February 2019**

Dear Dai Lloyd AM

When we gave evidence to the Health, Social Care and Sport Committee we were asked by David Rees AM to go back to our peers and ask them what things they think most need to change.

To make this happen we have worked with Carers Trust Wales to send a one-page form to all young carers services in Wales giving as many young carers as possible the chance to have their voices heard.

So far, we have had over 90 responses from young carers ranging in age from 8 to 24 from all across Wales. They have been supported by Network Partners of Carers Trust Wales, Action for Children, YMCA and Barnardo's to complete the form and return it to us and we are really grateful to them for their support.

We have also discussed this with the carers groups we represent on the Carers Trust Wales Youth Council and other young carers we know.

Although lots of different issues were raised, in our opinion there are 4 clear things that most young carers think need to improve:

- Awareness of young carers at school
- Opportunities to socialise with other young carers both at school and outside of school
- Chances to be active and to go on holiday with and without the people we care for
- Guaranteed funding for our young carers services so that we don't have to worry about losing the support we rely on

We think the Health, Social Care and Sport Committee of the National Assembly for Wales should listen to what young and young adult carers think is most important when making recommendations about what should change.

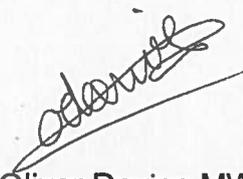
## Carers Trust Wales / Ymddiriedolaeth Gofalwyr Cymru

We were really grateful to have the chance to meet with you and the rest of the Committee on Young Carers Awareness Day. It meant a lot to us and all of the other young carers who were there that you listened to what we had to say.

We hope that this additional information will be useful for you and that you can use it to help make sure that all young carers in Wales are supported. It is important that more people are made aware of what young carers do and the importance of recognising and supporting us.

If we can help with anything else as part of this inquiry, please contact us through Kate Cabbage [kcabbage@carers.org](mailto:kcabbage@carers.org)

Yours sincerely



Grace Barton MWYP, Oliver Davies MWYP and Bethan Evans

Carers Trust Wales' Youth Council



## Agenda Item 2.7

Dai Lloyd AM  
Chair, Health, Social Care and Sport Committee  
National Assembly for Wales  
Cardiff Bay  
CF99 1NA

Dear Dai

### **Inquiry: Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers**

We are writing to you in response to issues raised regarding Carers Needs Assessments in the final evidence session of the above detailed inquiry.

As organisations representing carers, those that support carers and carers services across Wales, we are concerned by Welsh Government's written and oral evidence which suggests that rates of refused assessments can be equated to a lack of need for assessment.

Whilst we fully recognise that all carers may not need an assessment, we consider it important to note that there is little evidence which interrogates the reasons behind carers refusing assessments.

Through Carers Trust Wales' Network of carers services, which reaches more than 34,000 carers in Wales each year, we have consistently been told that there are several barriers to carers accessing assessments which include:

- Concern or fear about asking for or accepting help from social services
- Poor knowledge of rights or ability to self-identify as a carer
- Belief that the assessment won't lead to the type of support they need
- Low levels of awareness about the types of support that are available
- A lack of support to navigate what can feel like a complex system and overwhelming system

Carers Wales' Track the Act research found that of those carers who responded to its survey, 61% had not been given any advice about being a carer and 54% said they had not been offered an assessment (including a review of an assessment if one already existed). We are concerned that local authorities are not proactively identifying carers or giving them the information and advice they need including making carers aware that carers needs assessments exist. Carers Wales has

expanded questions in this year's survey to gather more detailed evidence regarding the reasons for refused assessments which will be reported in September.

We remain concerned that too many carers are unable to access Carers Needs Assessments despite them having a clear need for support. There are on-going examples of local authorities counting sending a letter and form out for a carer to complete as an offer of assessment. It is not unlikely that those carers who do not complete that form may be considered to have refused an assessment.

Additionally, we have examples of some local authorities discouraging carers from taking up the offer of an assessment on the grounds that the menu of services they can offer does not meet that individual carer's needs. Clearly, this is contrary to obligations set out under the Social Services and Wellbeing (Wales) Act.

Given that data collection is at best experimental, and carers' views on the reasons for refusing assessment have not been consistently sought or acted upon, we believe it is important for the committee to interrogate further why so many carers refuse assessment.

The evidence gathered by our organisations suggests that there is a gap between the number of carers who need support and the number of carers receiving a meaningful assessment. However, despite our collective best efforts there remains insufficient evidence to enable us to quantify the size of the gap.

We would strongly advise that as the committee considers the evidence presented through this inquiry, adequate weight is given to the importance of properly understanding carers' experiences and the way in which obligations under the Act are realised in practice.

If we can be of any further assistance on this issue, or at any point in your consideration of evidence, please do not hesitate to contact us.

Yours sincerely



Simon Hatch, Director, Carers Trust Wales  
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Claire Morgan, Director, Carers Wales  
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**Vaughan Gething AC/AM**  
**Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol**  
**Minister for Health and Social Services**



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref MA-L/VG/0005/19

Chair of Health, Social Care and Sport Committee  
Chair of Finance Committee

National Assembly for Wales  
Ty Hywel  
Cardiff  
CF99 1NA

18 February 2019

Dear Chairs,

I am writing to thank each of your Committees for their stage one scrutiny of the Autism (Wales) Bill, and provide a response to committees' report recommendations (Annex A) which were directed at the Welsh Government. As the Bill was not successful in the vote following the General Principles Debate on 16 January, my response reflects this decision as I have not commented on recommendations relating to the possible progress of the Bill.

I am pleased to be able to agree the remaining recommendations, although in some cases I provide further explanation about what Welsh Government intends to do.

I want to assure all members of our firm commitment to improving autism services. This will be achieved through the delivery of the ASD Strategic Action Plan, the development of the Code of Practice on the Delivery of Autism Services and by embedding the services and reforms we have introduced including maximising the impact of the significant additional financial resources that have been allocated. I will shortly publish a Written Statement confirming the Welsh Government's intention to step up the pace of improvements to autism services and to review the outcomes which are achieved.

Yours sincerely,

**Vaughan Gething AC/AM**  
**Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol**  
**Minister for Health and Social Services**

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

## Health Social Care and Sport Committee

**Recommendation 1.** *We recommend that the Welsh Government directs the integrated autism service to improve the consistency of the services across the regions to ensure a national approach and reports back to the Committee within six months. We also recommend that they produce clear public information to clarify what people can expect from the Integrated Autism Service.*

Agreed The Integrated Autism Service (IAS) is supported by the National Autism Team that is hosted by the Welsh Local Government Association and Public Health Wales. The Team facilitates a Heads of IAS group to promote collaborative working. Recent work has included reviewing and updating the specification for the service, and to agree outcome focussed service wide monitoring arrangements. I expect the revised national specification and monitoring arrangements to be available by April. Information on the IAS and autism resources is freely available on the ASDinfo Wales website [www.asdinfo.wales.co.uk](http://www.asdinfo.wales.co.uk). Each regional service will also produce their own communications materials.

The IAS has been designed to bridge an identified gap in services rather than replace existing support. The IAS will sometimes refer individuals to other mainstream services which are better placed to provide specialised support.

We are working to build autism knowledge and skills across public sector services through the resources and training being delivered by the National Autism Team and locally by the IAS teams. Examples of these resources can be found on the ASDinfo Wales website.

As each IAS has overlaid existing autism services in their regions, there will be some differences in how local services are delivered, to take account of variances such as the professional mix of staff, local geography and the services most in demand in any area. We aim to publish findings from the independent evaluation of the implementation of the service by the end of February, and we will carefully consider recommendations made there alongside those made by the scrutiny committees. We will set out further plans for evaluation and monitoring of our reforms as part of the annual report on the delivery of the ASD strategy in June 2019. We will send the Annual Report to each committee.

**Recommendation 2.** *We recommend that the Welsh Government increases the provision of direct ASD support services across Wales (beyond the services currently offered by the Integrated Autism Service), and ensures vital third sector services receive sustainable funding to continue and expand their specialist support services, which are providing direct frontline support and plugging the gaps which the Integrated Autism Service cannot deliver.*

Agreed The IAS is an additional service designed to increase capacity, local authorities and health boards should also have existing autism services which work alongside the IAS. From 2015/16 the Welsh Government placed the autism infrastructure grant of £40k per local authority in the Revenue Support Grant. This funding is available for local authorities to support autism services which could include securing third sector support. Also the Welsh Government Sustainable Social Services third sector grants scheme is specifically designed to provide national voluntary sector groups with funding to deliver community support services. The next grant will be available from April 2020 and we encourage voluntary

sector groups including those which provide specialist support services for autistic people to apply for funding through the competitive grant application process which will be advertised later in 2019.

***Recommendation 3.*** *We recommend the Welsh Government takes urgent action to address the clear need for employment support for adults with ASD. There must be a clear pathway for adults to be able to access support to assist them into employment. Careers Wales should play a greater role but there is also a case for providing additional funding to third sector agencies to deliver specialised employment support services.*

Agreed We are working to support autistic adults people who experience difficulties in accessing and maintaining employment, many of whom will have a wide range of skills and experience.

The National Autism Team and local autism leads have strong working relationships with the Department of Work and Pensions to assist their staff in supporting autistic people who are in receipt of out of work benefits, which are non-devolved.

Our Working with Autism programme delivered through the ASD National Autism Team is supporting Careers Wales and Job Centres to provide advice and support for individuals with autism seeking employment support. By the end of 2018, over 30,000 individuals have completed our ASD aware scheme (8,006 completed during 2018) and 1,210 have completed Working with Autism scheme. A further 263 have completed the Positive about Working with Autism HR scheme. The Autism Aware scheme is also now being rolled out to Welsh Government staff.

The Welsh Government is also working in partnership with the Big Lottery – Getting Ahead Two project which is a five year programme designed to support young people who have learning disabilities or autism into the workplace. This project is delivered by a third sector consortium and is in its third year. Up to November 2018, 200 autistic young people have been referred into the service, 170 have received a vocational profile, 160 have undertaken placements and 33 autistic young people are now in sustained employment.

Also in 2018, we published a cross-Government employability plan that set out our vision for making Wales a full-employment, high-tech, high-wage economy. At the centre of this ambition, we are committed to helping everyone achieve their full potential through meaningful employment, regardless of their ability, health issues, background, gender or ethnicity. We are supporting people who are not working with a particular emphasis on those who are economically inactive and less likely to be in contact with mainstream employment support. This will include supporting autistic people and we will investigate where more can be done to provide them with the tailored support they need.

The Employability Plan takes action in four distinct themes; providing an individualised approach to employment support, underlining the responsibility of employers to support staff, closing skills gaps and preparing for a radically changing labour market. Individualised support gives advisers the autonomy and flexibility to address the needs, strengths and ambitions of the person preparing for work.

**Recommendation 4.** *We recommend that the Welsh Government amends the Codes of Practice for Parts 3 (assessing the needs of individuals) and 4 (meeting the needs) of the Social Services and Well-being Wales Act 2014 to include specific provisions on ASD.*

Agreed The Welsh Government has published a consultation on our proposals for a Code of Practice on the Delivery of Autism Service on 30<sup>th</sup> November, which is open until 1 March 2019. This Code will be made under both the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006. The purpose of the Code will be to ensure that both statutory services and autistic people understand their rights and responsibilities under existing needs based legislation and codes of practice. The Code will seek to ensure services are adapted to meet the specific needs of autistic people.

**Recommendation 5.** *We recommend that the Welsh Government instructs Health Boards and local authorities to ensure there are multiple appropriate clear referral pathways available to all, including a specific primary care pathway, and that existing barriers between the health, care and education sectors are removed, for example to enable GPs to refer children for education support.*

Agreed Through the work of the Together for Children and Young People Programme, neurodevelopmental workstream, there are now nationally agreed pathways to access children's assessment services. The IAS is also developing national pathways for adult services as part of service improvement.

The consultation on the Code of Practice for the Delivery of Autism Services makes specific reference duties in relation to the provision of care and support pathways, this includes diagnostic pathways for assessment and diagnosis, to be aligned with social care pathways. There are also plans to require primary care pathways, particularly for GPs and to ensure there are appropriate pathways for autistic people with other co-existing conditions to access support which is appropriate for their needs.

**Recommendation 6.** *We recommend that it should be mandatory for all school staff (particularly teachers and teaching assistants) to receive training in awareness and understanding of ASD, during their initial teacher training and as part of their continuing professional development.*

Agreed We are currently reforming the way in which initial teacher education (ITE) is delivered in Wales. The ITE reforms require accredited ITE partnerships to design and deliver courses that support the four purposes of the new curriculum for Wales and address the six areas of learning and experience (AoLE) in order to develop future teachers to meet the needs of all learners, including learners with ASD. Furthermore a key element of our overall reform agenda has been to introduce a new more rigorous approach to the accreditation of programmes of ITE, and that these should be governed by the EWC so enabling the profession to set its own entry requirements. These new programmes will be available from September 2019.

New ITE Partnerships will develop approaches to assist aspiring teachers to understand the importance of research informed practice, so that teachers are taught the importance of keeping up to date with research and research on ASD, to inform their teaching

practice on an ongoing basis throughout their working lives. In addition all teachers in Wales are required to understand and be aware of the wellbeing, personal, emotional and social development of all learners.

The consultation on the Code of Practice for the Delivery of Autism Services includes a section dedicated to improving staff knowledge and skills. Statutory bodies will be expected to undertake autism training needs analysis for their staff, tailored to their professional needs. In relation to schools the National Autism Team have developed the Learning With Autism (LwA) programme aimed at increasing knowledge across teaching staff and learners, there are now packages available for early years, primary schools, secondary schools and further education. Applications for the LwA awards are being received on a daily basis. Our success so far is as follows.

- Primary Schools launched in March 2016: Almost 4500 teaching staff have completed the scheme, and almost 5,000 LSA's. We now have over 26,500 autism superheroes, 11,640 this year alone. There have been 111 schools awarded LwA whole school award certificate (more than 40 schools across Wales during 2018).
- Early Years: almost 1000 members of staff completed the scheme. 40 settings have been awarded their certificate. (35 more since January)
- Secondary Schools: more than 2000 teachers have completed the scheme and there have been 9161 pupils signed the pupil pledge (which is over 8,700 pupils undertaken the pledge since January 2018). 8 schools applied and successfully received their awards.

***Recommendation 7.*** *We recommend that the implementation of the Additional Learning Needs and Education Tribunal (Wales) Act 2018 is closely monitored to assess whether it meets the needs of children and young people with ASD considered 'high functioning' and who do not have a co-occurring learning disability.*

Agreed Under the Additional Learning Needs and Education Tribunal (Wales) Act 2018 ('the ALNET Act'), all children and young who are identified as having an additional learning need (ALN), which might include those with ASD considered high functioning, will be entitled to an individual development plan and associated rights and protections under that Act. The Welsh Government is committed to undertaking a post-implementation review of the ALNET Act five years after its commencement. This will assess the extent to which the ALNET Act has had a positive impact on children and young people with ALN in Wales.

***Recommendation 9.*** *We recommend that the Welsh Government's Code of Practice makes provision to ensure that individuals can access appropriate information and support in their language of choice.*

Agreed The consultation on the Code of Practice makes specific reference to the availability of services meet Welsh Language Standards and where required provide reasonable adjustments to ensure that autistic people with protected characteristics have equal access to services and support. We have also published an Easy Read version of the consultation on the proposals for the Code of Practice

## **Finance Committee**

**Recommendation 1.** *In future, should the Assembly vote in favour of the motion tabled in accordance with Standing Order 26:91 the Committee recommends that the Welsh Government commits to providing information to ensure that costs in an explanatory memorandum are as comprehensive and detailed as possible utilising cost information which the Welsh Government has available.*

Agreed. A letter from the First Minister, responding directly to the Committee's concerns was issued on 21 December 2018. The Welsh Government will provide information held by us, but we would not undertake any additional data gathering or bespoke data analysis etc., as this is the responsibility of the Member in Charge.



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8 Mawrth 2019

Dr Dai Lloyd AM/AC  
Cadeirydd y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon / Chair, Health, Social Care  
and Sport Committee  
Cynulliad Cenedlaethol Cymru / National Assembly for Wales  
Caerdydd / Cardiff Bay  
CF99 1NA

Annwyl Dai Lloyd

Many thanks for the opportunity to contribute evidence to your Committee during your scrutiny of the Autism (Wales) Bill.

While we recognise the Committee was not able to reach a consensus on whether legislation is the most appropriate vehicle, we welcome the Committee's view that there is a pressing need to improve support services for the 34,000 autistic people in Wales and their families.

The recommendations in the Committee's report reflect this and we would support the call for urgent action to be taken so that families do not have to struggle to access the services and support they need, and the improvements we all want to see can be achieved.

We understand that your Committee is due to consider the Welsh Government's response to your Stage 1 report shortly and would like to take this opportunity to make the Committee aware of some of our concerns in advance of that discussion.

While we welcome the fact that the Welsh Government is in agreement with eight of the nine recommendations made in your report, we are concerned that the accompanying comments in that response don't explain in sufficient detail the actions that the Welsh Government is taking to implement the recommendations it has agreed.

For example, based on the evidence it heard, the Committee recommended that the Welsh Government increases the provision of direct autism services, beyond what is currently offered through the integrated autism service. Concrete details on how the Welsh Government intends to deliver these autism service would be helpful so that autistic people know what is available locally.

The Committee heard specifically that the Social Services and Wellbeing Act had failed to deliver improved outcomes for autistic people, because the assessments are not appropriate and they are therefore wrongly denied the care and support they need. The Committee recommended amending the codes of practice issued under Parts 3 and 4 of the Social Services and Wellbeing Act to improve outcomes for autistic people. It's unclear how the Welsh Government intends to amend the codes under Parts 3 and 4 despite agreeing to the recommendation.

The Welsh Government has also agreed to the recommendation that it should be mandatory for all school staff to receive training in awareness and understanding of autism. The Committee will be aware that work on the Additional Learning Needs transformation programme is well underway and therefore presents an ideal opportunity to implement the Committee's recommendation. Again it would be helpful to know how the Welsh Government intends to take action here.

In addition, in a letter to Assembly Members dated 15 January 2019, the Minister committed to a programme of work the Welsh Government will undertake in the coming months to reform and improve autism services. This includes publishing an independent report on the integrated autism service by February 2019. We were disappointed that the full report was not made public and instead the Welsh Government published only preliminary findings.

Further reports include a review of the barriers to reduce waiting times due to be completed at the end of March; data on the 26 weeks waiting times available from April; and an annual report by June. All these reports will be useful evidence of the support and services available for autistic people. Assurances that there will be no further slippage or changes in publishing these reports as stated would be welcomed.

We look forward to hearing the Committee's views on its work in this area over the coming months. Should the Committee feel that this would require further information from the National Autistic Society Cymru, we would be happy to oblige.

Yn gywir iawn

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████████████████████, Rheolwr Materion Allanol / External Affairs Manager

By virtue of paragraph(s) vi of Standing Order 17.42

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